

Comprehensive Cancer Plan *for the* Alaska Tribal Health System

2011 to 2017



ALASKA NATIVE
TRIBAL HEALTH CONSORTIUM
CANCER PROGRAM



Kake, Photo © ANTHC Marketing

VISION

The Alaska Native people will be cancer-free

MISSION

Provide the Alaska Native people with cancer prevention, screening, diagnosis, treatment, survivorship, and palliative education and care through a comprehensive, integrated Alaska Native cancer program

GOAL

Reduce cancer death and disease among Alaska Native people

Dedication:

*Dedicated to Alaska Natives who make the cancer journey.
May their pain and suffering return as skills and knowledge
so that Alaska Natives and all people can be cancer-free.*

Acknowledgements:

To honor the waterways that are so important to Alaska Native life, the Alaska Native Tribal Health Consortium Cancer Program logo shows a boat with a cancer patient at the bow navigating the way. Behind the patient are family, friends, and healthcare providers supporting the cancer journey.

The patient is the focus of the journey and takes charge of fighting the disease—spiritually, mentally, emotionally, and physically. However, the patient does not make the journey alone.

We make the journey together.



Special thanks to:

The ATHS Cancer Plan Implementation Committee



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ALASKA TRIBAL HEALTH SYSTEM

Regional Health Consortia

Area Map Key by Region

REGION
NUMBER ORGANIZATION

	Alaska Native Tribal Health Consortium
1	Arctic Slope Native Association
2	Maniilaq Association
3	Norton Sound Health Corporation
4	Yukon-Kuskokwim Health Corporation
5	Bristol Bay Area Health Corporation
6	Aleutian/Pribilof Islands Association
7	Eastern Aleutian Tribes
8	Kodiak Area Native Association
9	Southcentral Alaska Alaska Native Medical Center (jointly managed by ANTHC & SCF) Southcentral Foundation
10	Chugachmiut
11	Copper River Native Association
12	Mt. Sanford Tribal Consortium
13	SouthEast Alaska Regional Health Consortium
16	Tanana Chiefs Conference

Tribal and/or Local Health Programs

REGION
NUMBER ORGANIZATION

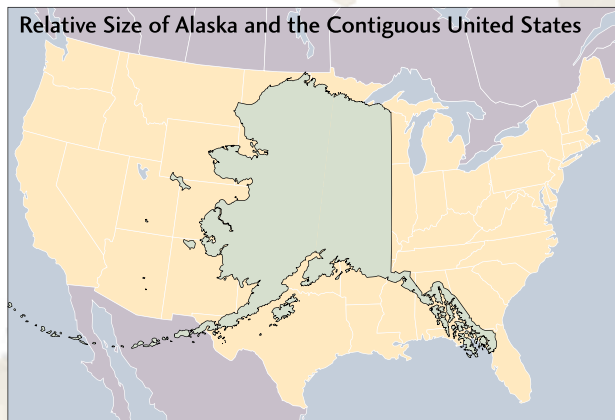
1	UIC (Barrow)
3	Diomedé, Native Village of
4	Kwinhagak, Native Village of Akiachak Native Community
6	St. George Traditional Council
8	Karluk, Native Village of
9	Southcentral Alaska • Eklutna, Native Village of • Ninilchik Village Traditional Council • Seldovia Village Tribe • Chickaloon Village Traditional Council • Knik Tribal Council • Tyonek, Native Village of • Kenaitze Indian Tribe, IRA
10	Valdez Native Tribe Eyak, Native Village of
11	Chitina Traditional Council
13	Hoonah Indian Association Yakutat Tlingit Tribe
14	Ketchikan Indian Corporation
15	Metlakatla Indian Community
17	Council of Athabascan Tribal Governments



ARCTIC OCEAN

BEAUFORT SEA

Relative Size of Alaska and the Contiguous United States



- Village
- Regional Hospital
- Alaska Native Medical Center (jointly managed by ANTHC & SCF)
- Regional Area Border
- Road



SCALE IN MILES

0 50 100 150 300

7/2004



Photo by Brian Adams

INTRODUCTION

Cancer continues to be the number one cause of death for the Alaska Native people. However, many people live a long time after a cancer diagnosis and cancer is now considered a chronic disease like heart disease. In general, chronic diseases should be diagnosed as soon as possible so treatment decisions can be made. Chronic diseases must also be continuously monitored throughout a person's life. The disability and risk of death from chronic diseases highlight the importance of prevention and screening for early diagnosis.

The first comprehensive cancer control plan for the Alaska Tribal Health System (ATHS) 2005-2010 was implemented in 2006. A review of that plan indicates that we have made progress in many of the cancer care components: prevention, screening/early detection, diagnosis/treatment, survivorship, palliative care, and research/surveillance (Appendix 3). However, there is still much work to be done to reduce the cancer burden in our efforts to make the Alaska Native people the healthiest people in the world.

Risk factors such as tobacco use and protective factors such as healthy food choices and regular physical activity play a major role in cancer prevention. Getting appropriate screening for breast, cervical and colon/rectal cancers is important for prevention and/or early detection. The earlier cancer is diagnosed, the more likely treatment will be successful. As more people live longer after a cancer diagnosis, we must support post-treatment issues and concerns in a more comprehensive way.

Our updated cancer plan (2011-2017) addresses all of the cancer care components, but we are placing particular emphasis on prevention, screening/early detection and long term survivorship. Identifying resources to complete the activities in the plan remains difficult, but we continue to work with many partners: tribal, governmental and private to identify funding to implement the cancer plan. The background information provided in the original plan is not duplicated in the 2011-2017 plan, but is available online. www.anthc.org/chs/crs/cancer/cancerprogrampublications

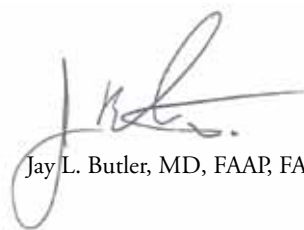
We work closely with other Alaska tribal and state cancer programs and with the state of Alaska comprehensive cancer program. These collaborations allow us to share cancer prevention resources and avoid duplicating programs and services.

This plan is a roadmap to help us fight cancer. Modifications will be made as needed. Alaska Native people or healthcare providers of Alaska Native people can make suggestions to add activities to the plan and the cancer plan steering committee that meets quarterly will review suggestions and recommend if it is appropriate or the resources are available to add to the annual work plan. Goals and objectives were selected after gathering information from tribal health organizations and directors; review of state, national and tribal needs and trends from many sources and experiences gathered working with healthcare providers, families and patients with cancer.

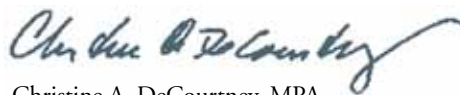
The plan does not include everything that must be done to make cancer a disease of the past. The fight against cancer will continue to be a long journey filled with setbacks and progress. It is a journey that requires everyone to do their part---including avoiding tobacco, increasing physical activity, practicing healthy eating, and improving screening tests, identifying new treatments and supporting a workforce to implement the cancer plan. Together we can make a difference.



Rita Stevens, BA



Jay L. Butler, MD, FAAP, FACP

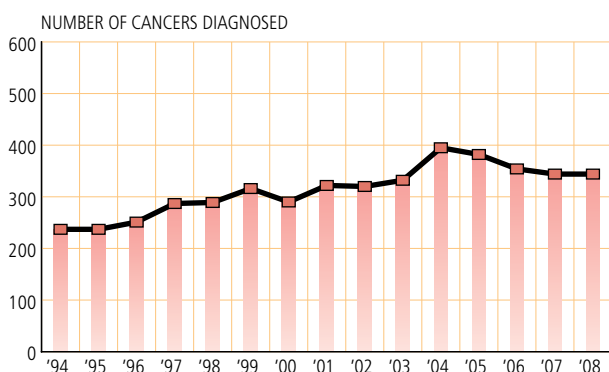


Christine A. DeCourtney, MPA

THE BURDEN OF CANCER IN ALASKA NATIVE PEOPLE

Cancer is the leading cause of death in Alaska Native people. Approximately 400 Alaska Native people are newly diagnosed with cancer each year, including *in situ* (tumors that have not spread) cancers. Cancer impacts patients, families, and communities as well as healthcare resources. Prevention and screening programs can help reduce the incidence of some cancers

Invasive Cancers Diagnosed in Alaska Native People (1994-2008) (Source ANTR 2012)

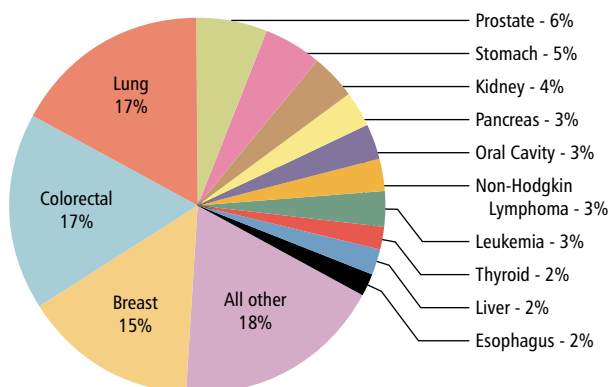


An increase in total population, aging of the population, an increase in life expectancy, better screening procedures, and an increase in risk factors, such as tobacco use contribute to the increase in the number of people diagnosed with cancer. The majority of cancers (93%) in Alaska Native people are diagnosed in individuals 50 years of age and older.¹

Incidence

In Alaska Native men and women combined, lung and colorectal cancer are the two most common cancers diagnosed followed by breast, prostate, stomach, kidney, oral cavity and pancreas. Leading cancers diagnosed among Alaska Native men are lung, colorectal, and prostate cancer. Leading cancers diagnosed among Alaska Native women are breast, colorectal, and lung.

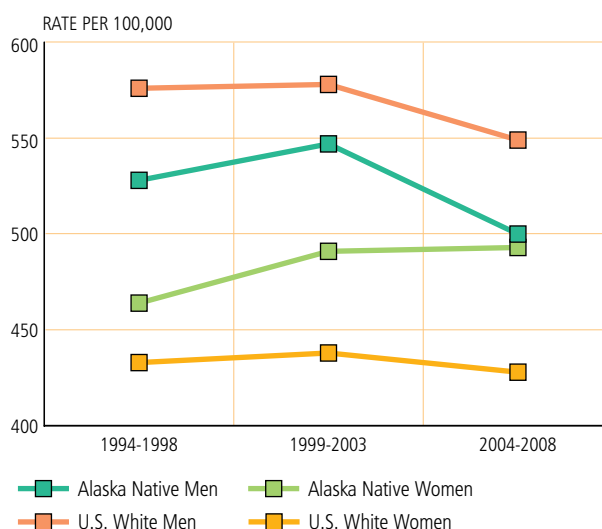
New Invasive Cancers Diagnosed in Alaska Native People (2004-2008) (Source ANTR 2012)



The cancer incidence rate (newly diagnosed cancers per 100,000 people) in the Alaska Native people increased 8% between the five year periods of 1984-1988 and 2004-2008.

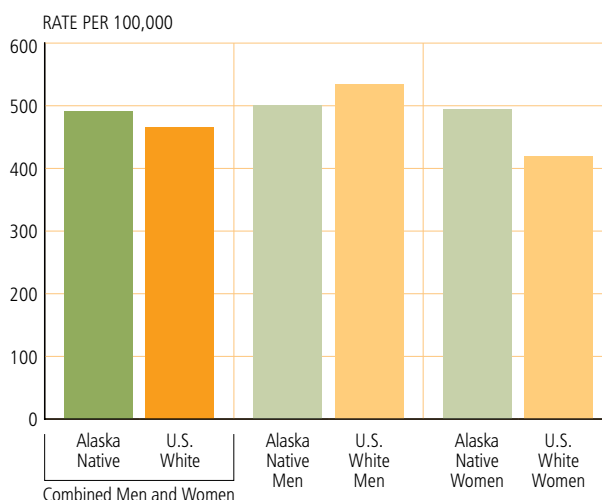
For the most recent five year period (2004-2008) the cancer incidence rate among Alaska Native men for all cancer sites combined declined. Incidence rates for Alaska Native women remained the same. In contrast, rates for both U.S. White men and women declined during the 2004-2008 period.

Five-Year Average Annual Age-Adjusted Cancer Incidence Rates (1994-2008) (Source ANTR 2012)



Cancer incidence among Alaska Native men is similar to the rate in U.S. White men, but the rate for Alaska Native women is 20% higher than that of U.S. White women.

Incidence Rates for All Cancers in Alaska Native and U.S. White People (2004-2008) (Source ANTR 2012)

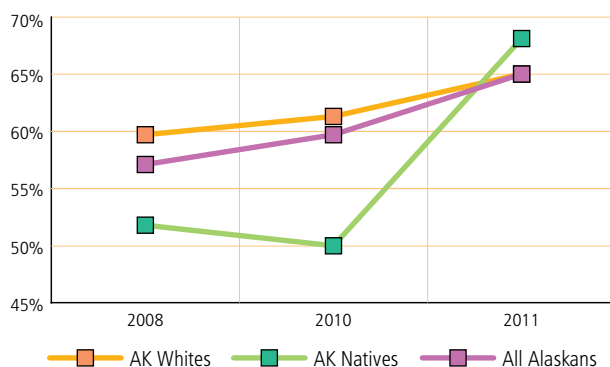


Patterns of cancer for Alaska Native people differ from all other racial groups in the U.S. including Whites, Blacks, American Indians and other minority populations. Site specific cancer incidence rates among Alaska Native people significantly exceed rates of cancer in U.S. Whites for lung, colorectal, stomach, kidney, pancreas, esophagus, nasopharynx and biliary tract. On the other hand, cancer incidence rates in Alaska Native people are lower than U.S. Whites for cancers of the prostate, uterus, urinary bladder and thyroid, and for melanoma, Hodgkin and non-Hodgkin lymphoma and lymphocytic leukemia.

When diagnosed, all cancers are “staged”, a process which determines how far a cancer has spread from the original site to other parts of the body. The earlier cancer is diagnosed, the better the likelihood that successful treatment can be given. Breast, cervical and colorectal cancers can be detected at earlier stages through regular screenings.

In 2011, colorectal cancer screening among Alaska Native people was higher than screening rates for Alaska White people and all Alaskans combined. Early detection and removal of polyps can prevent the development of more serious disease.

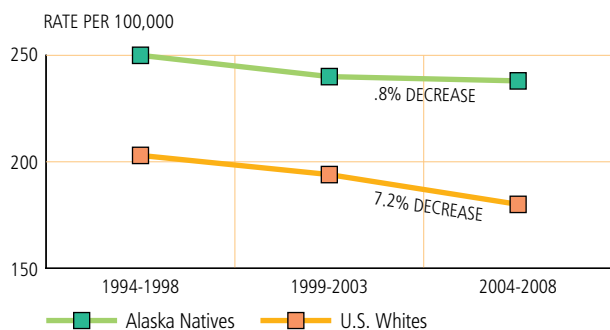
Percent of People Ever Screened for Colorectal Cancer (Alaska BRFSS 2008, 2010, 2011)



Mortality

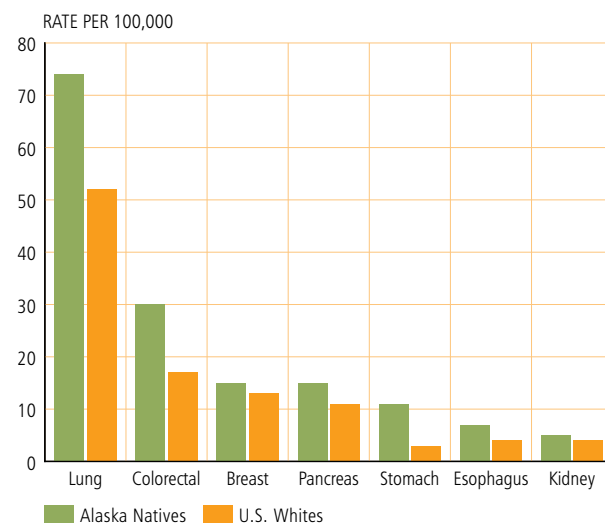
The age-adjusted cancer mortality rate (2004-2008) is significantly higher in Alaska Native people than in U.S. White population (238/100,000 vs 180/100,000).² Mortality can be affected by stage at diagnosis and access to treatment.

Five-Year Average Annual Age-Adjusted Cancer Mortality Rate, Alaska Native and U.S. White People (1994-2008) (Source ANTR 2012)



Leading Site Specific Cancer Mortality Rates in Alaska Native People and U.S. White Populations (2004-2008)

(Source ANTR and NCI SEER Stat, 2012)



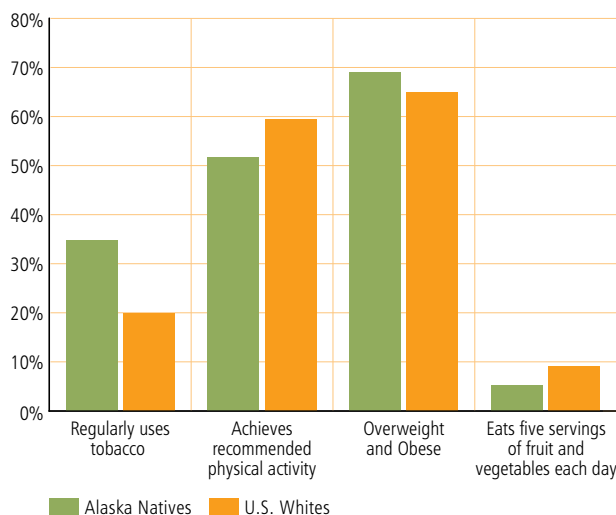
Survival

The State of Alaska Cancer Registry is developing a state-wide cancer survival rate report, expected to be completed by December, 2012.³

Cancer Risk

Certain behaviors or exposures, like tobacco use, are known to increase an individual's chance of developing cancer and other chronic diseases (risk factors).⁴

Chronic Disease Risk Factors for Alaska Native and U.S. White People (Source Alaska BRFSS 2011)



Endnotes:

- 1 Alaska Native Tumor Registry, Alaska Native Epidemiology Center, DCHS, www.anthc.org
- 2 Ibid
- 3 Five-year relative survival rates describe the percentage of patients with a disease that are alive five years after diagnosis divided by the percentage of the general population of corresponding sex and age that are alive after five years.
- 4 Ibid

PREVENTION

Cancer continues to be the leading cause of death among Alaska Native people. Cancer is not just one disease, but more than 100 different diseases. Cancer is caused by a complex mixture of factors related to lifestyle, heredity, and environment. Some of these factors are within an individual's control, while others are not. A person can choose not to use tobacco, but has no control over inherited factors associated with sex or race. However, even if there are inherited factors, there is still much that can be done to prevent cancer.

Risk factors are conditions that increase the likelihood that cancer might occur. Protective factors are conditions that decrease the likelihood that cancer might occur. For example, smoking is a risk factor for lung and other cancers, whereas maintaining a healthy weight is a protective factor for breast cancer and many other cancers.

Avoiding excessive alcohol consumption, being physically active, maintaining a healthy weight, and eating foods low in fat and high in whole grains, fruits and vegetables may be protective factors. The impact of environmental contaminants that cause cancer, with the exception of tobacco exposure, appear to be much smaller.

Prevention messages and activities are similar for many chronic diseases including diabetes, heart disease, obesity and cancer. Coordination among chronic disease programs encourages consistent messaging and responsible use of resources.

TOBACCO USE

Smoking is the leading cause of premature, preventable death in the United States. Lung cancer is the leading cause of cancer deaths among Alaska Native people. Nationally, tobacco use accounts for at least 30% of all cancer deaths and 80% of lung cancer deaths.¹ The number of cancer deaths related to tobacco use among Alaska Native people is likely to be much higher due to the increased use of tobacco by the Alaska Native population.

Cigarette smoking and exposure to tobacco smoke cause more than 440,000 early deaths each year in the United States.² Of these premature deaths, about 41% are from cancer, 33% are from heart disease and stroke and 26% are from lung disease.³

Inhaling the complex chemical mixture of combustion compounds in tobacco smoke causes adverse health outcomes, particularly cancer and cardiovascular and pulmonary diseases, through mechanisms that include DNA damage, inflammation, and oxidative stress. The burden of tobacco use among Alaska Native people is significant both in quality and length of life and monetary costs. The direct medical cost of tobacco related chronic diseases for all Alaskans is estimated to be over \$325 million annually and an additional \$221 million in lost productivity due to tobacco-related illness and deaths.⁴

In 2010, almost twice as many Alaska Native people were estimated to be current smokers than non-Native Alaskans (41% vs. 18%).⁵ Similarly, in 2010, Alaska Native people were almost five times as likely as non-Native Alaskans to be smokeless tobacco users (16% vs. 3%).⁶ Tobacco rates among Alaska Native people have not decreased since the early 1990s. The smokeless tobacco most commonly used is Copenhagen®. "Iqmik" is a homemade form of smokeless tobacco, sometimes referred to as "Blackbull" or "Dediguss" and is used among some Alaska Native populations. It is prepared by mixing leaf tobacco with ash derived from burning punk fungus, alder or willow bushes, or driftwood.

Youth Tobacco Use Rates

Alaska Native youth are three times more likely than U.S. White youth to have tried smoking before age 13 (21% vs. 7%).⁷ Not only do they start smoking at a young age, but Alaska Native high school students are also more likely than U.S. White high school students to have ever tried smoking, to currently be a smoker, and to smoke frequently (20% vs. 5%).⁸ They also use spit tobacco at higher rates than non-Native youth (12% vs. 6%).⁹

Pregnant Women Tobacco Use Rates

A higher percentage of Alaska Native women smoke cigarettes during the last three months of their pregnancy when compared to non-Native women (30% vs. 10%).¹⁰ There is also a relatively high rate of spit tobacco use among Alaska Native women (18% vs. 0.3%) with the highest use in women who live in Western Alaska (58%).¹¹ Research on tobacco use shows that smoking during pregnancy increases the risk of pregnancy complications, premature delivery, low birth rate infants, still birth and Sudden Infant Death Syndrome.

Secondhand Smoke

Tobacco kills not just those who choose to smoke, but also non-smokers who are exposed to smoke from other people's cigarettes. In 2008, it is estimated that second hand smoke kills approximately 50,000 Americans each day.¹² Exposure is associated with an increased risk of lower respiratory tract infections such as bronchitis and pneumonia. It increases the risk and severity of ear infections and asthma symptoms in children. As of 2012, local clean indoor air policies cover 56% of the Alaskan population with some 100% smoke free laws.¹³

Tobacco Use Screenings

Screening for tobacco use by health care providers at every patient visit reliably decreases tobacco use.¹⁴ Tribally operated facilities are encouraged to utilize tobacco screening in their practices.

Since 2003, the ANTHC Tobacco Program has provided as-

assistance to tribal organizations to develop capacity and infrastructure needed for comprehensive tobacco control programs for Alaska Native people. It provides assistance in developing, expanding or revitalizing nicotine dependence treatment services. Making cessation services available and accessible are critical parts of a comprehensive approach to reducing tobacco use among current users. The program uses a well researched behavior modification strategy and includes pharmacological aides.

Tobacco Policy

Policy changes including clean indoor air legislation and taxation of tobacco products limit the availability of tobacco and locations where tobacco use is allowed. Smoke-free policies are the most economic and effective approach for providing protection from exposure to secondhand smoke.¹⁵ ANTHC partners with the Alaska Tobacco Control Alliance (ATCA), a statewide organization of health care providers, non-profit agencies and others who collaborate in areas of policy and advocacy with the mission of reducing death and disease as a result of tobacco use.

Goals, Objectives & Strategies for Tobacco Use Prevention

GOAL: Reduce cancer incidence, illness, and death due to tobacco use among Alaska Native people.

OBJECTIVE PT1: Expand and develop the ATHS capacity to address tobacco dependence by incorporating tobacco control systems in twelve tribal organizations by 2017.

Baseline: *Nine tribal organizations have incorporated tobacco control systems in 2011 (ANTHC Tobacco Program)*

Activity a: Educate policy decision makers to increase funding for tobacco control programs in Alaska.

Activity b: Support state funding to encourage systemic, sustainable change to reduce tobacco-related illness and death.

Activity c: Coordinate with tobacco partners and other chronic disease programs to implement evidence-based brief interventions and tobacco systems.

Activity d: Coordinate with the State of Alaska Quit Line to expand the number of tobacco users who have access to cessation services.

Activity e: Investigate using a standard Nicotine Replacement Therapy (NRT) formulary throughout the ATHS.

OBJECTIVE PT2: Increase the number of patients enrolled in ATHS tobacco treatment by 25% by 2017.

Baseline: *11,753 enrollees in 2011 (ANTHC Tobacco Treatment Database)*

Activity a: Expand the number of health care providers offering tobacco treatment.

Activity b: Improve systems by which a health care provider can refer patients to tobacco treatment.

OBJECTIVE PT3: Increase the percentage of Alaska Native patients screened for tobacco use in ATHS health care facilities to 75% by 2017.

Baseline: *61% (GPRA 2010)*

Activity a: Expand tobacco cessation knowledge and application of the "5A's" (Ask, Advise, Assess, Assist, and Arrange) by offering ongoing training to ATHS providers.

Activity b: Improve systems to remind health care provider to ask each patient at each visit if they use tobacco and determine their readiness to quit and advise them accordingly, based on the USPHS Clinical Practice Guidelines.

OBJECTIVE PT4: Reduce the percentage of adult Alaska Native smokers to 33% by 2017.

Baseline: *36% (BRFSS 2011)*

Activity a: Ensure that all Alaska Native people who wish to quit tobacco have access to evidence-based cessation interventions.

Activity b: Increase Alaska Native specific tobacco control initiatives to assure comprehensive, culturally appropriate media messages reach the intended audience.

Activity c: Support advocacy efforts to pass a statewide clean indoor air policy and increase tobacco taxes.

OBJECTIVE PT5: Reduce the percentage of adult Alaska Native spit tobacco users to 10% by 2017.

Baseline: *16% (BRFSS 2010)*

Activity a: Ensure that all Alaska Native people who wish to quit spit tobacco have access to evidence-based cessation interventions.

Activity b: Increase Alaska Native specific spit tobacco control initiatives to assure comprehensive, culturally appropriate media messages reach the intended audience.

Activity c: Support advocacy efforts to pass an increase in local and state spit tobacco taxes.

OBJECTIVE PT6: Reduce the number of pregnant women who smoke during the last three months of pregnancy to 25% and number of pregnant women who use spit tobacco to 15% by 2017.

Baseline: 30% smoke, 18% use spit tobacco/lqmik (PRAMS 2008)

Activity a: Develop and assess the effectiveness of Alaska Native specific tobacco use interventions for women of reproductive age, including pregnant and post partum women.

Activity b: Increase Alaska Native specific tobacco control initiatives and educational resources targeting pregnant and post partum women to assure comprehensive, culturally appropriate media messages reach the intended audience.

OBJECTIVE PT7: Reduce the percentage of Alaska Native youth smokers to 15% by 2017.

Baseline: 20% of Alaska Native youth smoke tobacco (YRBS 2011)

Activity a: Support Alaska Native specific tobacco control media and education initiatives to assure comprehensive, culturally appropriate media messages reach Alaska Native youth.

Activity b: Encourage partners within rural communities ask parents of young children and youth, if they use tobacco or expose family members to second hand smoke and then determine their readiness to quit and advise them accordingly.

Activity c: Partner with non healthcare providers to address tobacco use with parents of young children (Don't start!) at the community level.

OBJECTIVE PT8: Support collaborative advocacy efforts to pass clean indoor air policies and tobacco tax increases at local levels and state-wide.

Baseline: No statewide clean indoor air policy exists in 2010

Activity a: Assist with efforts to establish statewide clean indoor air policy through collaboration with Alaska Tobacco Control Alliance (ATCA) and other advocacy partners.

Activity b: Assist with efforts to increase local or state-wide tobacco taxes through collaboration with ATCA and other advocacy partners.

Activity c: Encourage the Alaska Federation of Natives to pass a resolution supporting a statewide clean indoor air ordinance.

deaths expected to occur in 2011 in the United States are attributed to poor nutrition, physical inactivity, overweight and obesity.¹⁶

Traditional Foods

Alaska Native people have relied on the land and sea to provide them with a healthy diet. The diversity of climates and geography in the state has led to many different adaptations in lifestyle and foods. Traditional foods in general are much healthier than store-bought foods, being higher in healthy fats and lower in saturated fats, vitamins A and C, and minerals. Mothers of young children have the opportunity to introduce traditional foods to infants and young children. Changes to Women Infant and Children (WIC) program might allow them to choose these foods over the Western options currently allowed under the WIC program.

Changes in Diet

Over the last 100 years Alaska Native people have experienced profound cultural upheaval and change. Western foods, such as coffee, tea, sugared beverages, bread, rice and potatoes are now widely available in village stores. Factors that affect cancer risks include the type of food eaten, the preparation method, portion size, variety and overall caloric balance.

Diet and Disease

Current scientific understanding about the relationship between diet and disease is limited. However, research studies have associated dietary habits with some cancer risks. Studies have shown that a healthy diet with appropriate caloric intake, reduced animal fat, reduced alcohol consumption and increased vegetable and fruit consumption can reduce the risks of certain kinds of cancer such as breast, colon, lung and prostate cancer. Research also suggests people who eat a diet that largely includes salted, pickled or smoked foods are at a greater risk of stomach cancer.¹⁷

Obesity

In addition to the cancer risk associated with specific diet components, overweight and obesity are also associated with many cancers including cancers of the colon, breast, endometrium, kidney, esophagus, gallbladder, thyroid and pancreas.¹⁸ The percentage of cases attributed to obesity varies widely for different cancer types but was as high as 40% for some cancers, particularly endometrial and esophageal cancers.¹⁹

Goals, Objectives & Strategies for Nutrition

NUTRITION AND OBESITY

Approximately one-third of the more than half-million cancer

GOAL: Alaska Native people will make healthy nutrition choices for cancer prevention.

OBJECTIVE PN1: Increase to 32% the proportion of Alaska Native adults 18 and older who are at their normal weight with a Body Mass Index (BMI) below 25 by 2017.

Baseline: 27.5% (BRFSS 2009)

Activity a: Provide resources for Alaska Native people about the links between diet and cancer, including the importance of maintaining a diet rich in plant-based foods, reducing the consumption of store-bought animal fat and attaining and maintaining healthy body weight.

Activity b: Provide resources for health care providers to increase their capacity to educate Alaska Native people on the importance of maintaining a healthy diet.

Activity c: Provide resources for new mothers on the importance of the early introduction of traditional foods for infants and young children.

Activity d: Revise Traditional Food Guide (published in 2008) to expand distribution to cancer survivors, providers, teachers and general public for use in traditional and non-traditional settings.

Activity e: Study options for potential changes in WIC program to allow traditional foods.

Activity f: Develop booklet for WIC program to intro-

duce traditional foods to children during infancy.

Activity g: Support the inclusion of traditional foods in daily diets of youth in residences and institutions where there is a high percentage of Alaska Native youth.

Activity h: Encourage drinking water for increased hydration and in place of soft drinks and other sugared drinks.

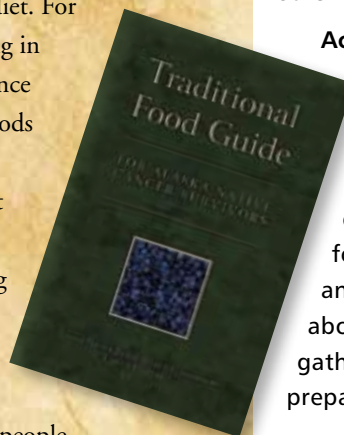
Activity i: As a third component of the traditional Native food guide activities, develop a DVD focusing on elders and youth learning about traditional gathering and food preparation.

Traditional Food Guide

Each year approximately 400 Alaska Native people are diagnosed with cancer. A challenge for cancer patients is maintaining a healthy diet. For Alaska Native cancer patients living in rural Alaska, there is a strong reliance on traditional animal and plant foods gathered from the land and sea. Traditional foods are an important part of the Alaska Native culture. The gathering, hunting, preserving and eating of traditional foods is more than just a diet—it's a way of life. A subsistence lifestyle has long connected Alaska Native people with the land and sea through celebrated rituals and practices passed down from generation to generation. "Without ritual, without storytelling, without the drum, subsistence is only food," Andrew Paukan.

The Traditional Food Guide for Alaska Native Cancer Survivors was published by the Cancer Program in April 2008. The goal of developing the guide was to provide easy-to-understand nutrition information for cancer patients and families. It is also designed as an evidence-based resource for healthcare teams to encourage the inclusion of traditional foods in cancer patient diets. Now in its third printing, the book is considered to be the best guide to Alaska's wild foods and a healthy lifestyle nutrition resource.

The guide is available at no cost to Alaska Native cancer patients. Others can purchase it for a nominal cost. Funds from the sales are used to reprint the book. For more information or to order a copy of the book contact Karen Morgan at kmmorgan@anthc.org or (907) 729-4491.



OBJECTIVE PN2: Reduce the percentage of Alaska Native students who are overweight or obese to 15% overweight and 10% obese by 2017.

Baseline: 17% overweight, 12% obese (YRBS 2009)

Activity a: Identify barriers to healthy eating in communities. Work with diabetes and other tribal programs to identify ways to overcome barriers.

Activity b: Develop an activity workbook for Alaska Native students aged 8-10 emphasizing the importance of making healthy food choices including traditional foods.

Activity c: Utilize existing adolescent social networking sites to introduce use of traditional foods.

OBJECTIVE PN3: Increase to 18% the proportion of Alaska Native adults 18 and older who eat at least five servings of fruits and vegetables every day by 2017.

Baseline: 15% (BRFSS 2009)

Activity a: Develop educational materials for Alaska Native adults to increase their awareness of the importance of eating five or more servings of fruits and vegetables every day.

Activity b: Introduce material to communities providing information on plate sizes and percentages of vegetables, protein and carbohydrates.

OBJECTIVE PN4: Increase to 18% the proportion of Alaska Native students who eat at least five or more servings of fruits and vegetables every day by 2017.

Baseline: 16% (YRBS 2009)

Activity a: Develop media messages aimed at Alaska Native adolescents to increase their awareness of the importance of eating five or more servings of fruits and vegetables every day.

Activity b: Identify tribal health program partners to collaborate with to deliver effective culturally appropriate services and education.

Activity c: Partner with hospitals in and outside of Alaska to support availability of traditional foods for Alaska Native patients who must remain out of state for care.

Changes in Physical Activity

Similar to diet changes, physical activity patterns among Alaska Native people have changed due to Western influences. Traditional subsistence lifestyles were characterized by physical demands of hunting, fishing, and food gathering. Other typical traditional physical activities included travel on snow by dogsled, travel on land by walking, travel on water with a paddle, wood cutting by handsaw, water hauled by hand, and clothes washed by hand. Although many of these traditional activities are still practiced, their frequency continues to decline along with

increasing modernization of Alaska village life and availability of mechanized vehicles.

The lack of physical activity is increasingly recognized as a risk factor for cancer. Many studies in the United States and around the world have consistently

found that adults who increase their physical activity, either in intensity, duration, or frequency, can reduce their risk of developing colon cancer by 30% to 40% compared to those who are sedentary.²⁰ Other studies indicate that physically active women have a lower risk of developing breast cancer than inactive women and demonstrates links between physical activity and a reduced risk of cancers of the prostate, lung, and lining of the uterus.²¹ Despite these health benefits more than 50% of Americans do not engage in enough regular physical activity.²²

Physical activity is important in maintaining a healthy body weight, and has positive effects for overall health. Although regular physical activity has been shown to have a beneficial impact on numerous chronic diseases, including cancer, many Alaska Native people are more sedentary than recommended and report less physical activity than non-Native Alaskans (65% vs. 74%).²³

Children's Activity Guide

The Traditional Food Guide Activity Book is an offshoot of the Traditional Food Guide for Alaska Native

Cancer Survivors. The activity booklet targets 8-10 year old Alaska Native children and provides nutrition information in a fun, easy to understand format, with importance placed on traditional Native foods as part of a healthy diet. Suggestions for healthy lifestyle choices and nutrition habits are highlighted to help children make informed and responsible decisions to reduce their risk for obesity, cancer, and other diseases.

It is provided free of charge to classrooms outside the Anchorage area. The book, in its third printing, has been included in health curriculums for 70 schools.

It is also very popular with many other groups. For more information about the activity booklet, contact Karen Morgan at kmmorgan@anthc.org or (907) 729-4491



PHYSICAL ACTIVITY

Physical activity, essential to overall health, can help control weight, reduce the risk of heart disease and cancer, strengthen bones and muscles, and improve mental health.

Barriers to Physical Activity

Alaska has many barriers to physical activity, including extreme temperatures and seasonal daylight limitations. There are special issues to be aware of when exercising in the cold outdoors, such as hypothermia and frostbite. Furthermore, the size of the state and the limited availability of sports facilities (for example gyms

and swimming pools) impact physical activity programs. However, some communities are developing outdoor programs such as cross country skiing. Any physical activity programs for Alaska must take into consideration the length of winter and design appropriate outdoor and indoor activities that are enjoyable and safe for those of varying physical abilities.

Recommended strategies and appropriate measurements are needed to assess the effectiveness of community initiatives to create environments that promote good nutrition and physical activity. In 2009, the CDC initiated the Common Community Measures for Obesity Prevention Project (the Measures Project). The objective of the Measures Project is to identify and recommend a set of strategies and associated measurements that communities and local governments can use to plan and monitor environmental and policy-level changes for obesity prevention. The six categories are:

- 1) strategies to promote the availability of affordable healthy food and beverages,
- 2) strategies to support healthy food and beverage choices,
- 3) strategies to encourage breastfeeding,
- 4) strategies to encourage physical activity or limit sedentary activity among children and youth,
- 5) strategies to create safe communities that support physical activity, and
- 6) strategies to encourage communities to organize for change.

Goal, Objectives & Strategies for Physical Activity

GOAL: Alaska Native people will make healthy physical activity choices for cancer prevention.

OBJECTIVE PP1: Increase to 70% the proportion of Alaska Native adults 18 and older who meet the 2008 Physical Activity Guidelines for Americans by 2017. (www.health.gov/paguidelines/pdf/paguide.pdf)

Baseline: 65% (BRFSS 2009)

Activity a: Increase public awareness of the benefits of physical activity.

Activity b: Encourage communities to provide physical activity opportunities and establish policies that promote physical activity.

Activity c: Develop culturally appropriate media campaign emphasizing unique in-home small space opportunities for brief bursts of activity.

OBJECTIVE PP2: Increase to 37% the proportion of Alaska Native high school youth who were physically active for a total of at least 60 minutes per day for five or more of the past seven days by 2017.

Baseline: 35% (YRBS 2009)

Activity a: Increase the number of schools that provide physical activity opportunities and establish policies that promote physical activity.

Activity b: Encourage safe areas for physical activity including playgrounds, sidewalks, and designated areas for walking, basketball, baseball, and similar activities.

Activity c: Develop campaign to reduce “screen” time and increase physical activity.

ENVIRONMENTAL CONTAMINANTS

Alaska Native people live in one of the healthiest environments in the world, characterized by clean air and water and an abundance of wild foods. There are no major manufacturing plants in the state that contribute to pollution and other environmental concerns. One major area of concern is both existing and proposed mines. There are instances, however, when Alaska Native people may be exposed to environmental contaminants in concentrations which do pose a risk, such as during renovations in a home that contains asbestos, eating contaminated food, or drinking water from a well that has high levels of arsenic.

Cancer Prevention and Relative Risk

When considering cancer prevention, it is important to have an appreciation of relative risk. In the case of contaminants, perception of risk is often greater than actual risk. This is partially due to the fact that people are exposed to contaminants through the essential things that they rely upon every day: air, water, food, and consumer products. Additionally, the high degree of attention paid by the media to contaminants may distort perception.

The data on contaminant exposure, particularly among Alaska Native people, is far from complete. It will take years before health implications are clearly understood. The current understanding is that known risks due to contaminants may be relatively small compared with risk factors associated with tobacco use and obesity.

Contaminants Account for Small Percentage of Cancers

During the past three decades, awareness has grown about the increase of cancer among Alaska Native people. With cancer rates rising, Alaska Native people have questions about the connection

between contaminants and cancer, and about the safety of their homes, communities, and the food upon which they depend. It is not known how many cancers diagnosed in Alaska Native people can be attributed to environmental contaminants.

At this time there is limited scientific data on contaminant related cancer incidence among Alaska Native people. Unlike other causal factors such as tobacco, poor nutrition or infectious agents, no cancer clusters have been found that can be singularly or primarily identified with everyday contaminant exposure. There are instances where, due to localized contaminant problems such as industrial use, military activity, or presence of a known hazardous waste, traditional foods should be harvested with caution. In locations where there has been a contaminated site designation by the State of Alaska or where local knowledge indicates that there may be a threat to food safety, restrictions on some wild food consumption may be necessary. In these locations, guidance from public health and environmental experts is warranted to determine what is safe and what should be avoided.

Traditional Native Foods

Studies to date have shown traditional foods are safe and the benefits outweigh the small amount of risk associated with trace levels of contaminants. Even store bought foods may not be free of contaminants. Based upon current knowledge it is recommended that consumption of traditional foods be encouraged for good nutrition and overall wellness.

Providing reliable information and raising awareness about the relative risks associated with environmental contaminants in the diet is an important prevention strategy for reducing cancers associated with diet and obesity, as well as other chronic illnesses such as diabetes and heart disease.

Goal, Objectives & Strategies for Environmental Contaminants

Goal: Reduce Alaska Native peoples' exposure to harmful levels of carcinogenic environmental contaminants.

OBJECTIVE PE1: Educate Alaska Native people about ways to reduce harmful exposure to contaminants.

Baseline: *Currently there are studies underway within ANTHC on the impact and health effects of climate change and large development projects. The ANTHC publication "Traditional Food Guide" is available statewide.*

Activity a: Raise awareness of the benefits and risks associated with traditional diets.

Activity b: Increase awareness about health risks associated with asbestos and radon exposure.

Activity c: Develop culturally appropriate materials that

discuss the possibility of environmental contamination, but highlighting that other changeable risk factors including tobacco and obesity are more harmful to one's health.

INFECTIOUS AGENTS

Certain viruses and bacteria, such as HPV, Hepatitis B, Hepatitis C, Epstein-Barr, Kaposi's sarcoma-associated Herpes virus, and *Helicobacter pylori* (*H. pylori*) are proven carcinogens.

Human Papilloma Viruses

Virtually all cases of cervical cancer are linked to Human Papilloma virus (HPV), an extremely common sexually transmitted infection that typically does not have symptoms. Of the 30 known types of HPV that are sexually transmitted, more than 13 types may lead to cervical cancer. Two of these types, HPV16 and 18 are associated with 70% of all cases of cervical cancer.²⁴

The HPV vaccines are given through a series of three injections over a six-month period. One vaccine would protect against four types of HPV, including two that cause most (70%) cervical cancers. These vaccines have been found to be highly effective in preventing infection with the targeted types of HPV.

In June 2007, The HPV vaccines became available through the State of Alaska Immunization Program. The 2004-2008 cervical cancer rate is similar among Alaska Native women and U.S. White women; however the burden of pre-cancerous lesions is high.²⁵ Due to the fact that these vaccines will not protect against all types of HPV, they will not prevent all cases of cervical cancer. Cervical screening (pap tests) will continue to be necessary.

Hepatitis B and Hepatitis C

Infections with hepatitis B (HBV) and hepatitis C (HCV) viruses can result in liver cancer. The rising incidence of liver cancer in the United States is thought to be due to HCV. HBV infection risk factors include occupational exposure to blood products, injection drug use, and high-risk sexual behavior (unprotected sex with multiple partners). Currently there are vaccines for HBV, but not HCV.

In the early 1970's, Alaska Native people were known to have a high rate of HBV infections. The Alaska State Hepatitis B Virus Immunization Program began in late 1982. No child born in Alaska, since HBV immunization became available, has been diagnosed with hepatocellular cancer, a cancer diagnosed in Alaska Native children prior to the availability of HBV immunization. Alaska has gone from one of the highest rates of acute Hepatitis A statewide and B in Alaska Native people in the U.S. to one of the lowest rate in the world (<1/100,000).

Screening of carriers has led to detection of liver cancer at an earlier stage and contributed to improved survival. Indeed, 60% of Alaska Native people with liver cancer diagnosed from 1984 to 1994 had liver disease detected at an early stage, compared to 21% of U.S. White patients with liver cancer.²⁶

Epstein-Barr virus and Kaposi's Sarcoma-Associated Herpes Virus

Epstein-Barr virus (EBV) is a virus that causes infectious mononucleosis, a benign disease generally diagnosed in young adults. Almost all persons are infected at sometime in their lives with EBV and at earlier ages in developing countries than in developed nations. It has been associated with some types of lymphoma and nasopharyngeal carcinoma, a cancer that occurs at very high rates in Alaska Native people. Another cancer-associated virus is Kaposi's sarcoma-associated herpes virus; infection only occurs through close person-to-person contacts.

Helicobacter Pylori

H. pylori are bacteria that can live in the stomach and duodenum. It is the most common cause of ulcers. It is not known how *H. pylori* passes from one person to another, but the bacterium have been found in saliva, dental plaque, and in the stools of children. Close contact with others in households may increase the spread of infection.

H. pylori infection is very common in the United States, but most people do not have any symptoms. Only a small percentage goes on to develop any disease. In addition to ulcers, infection with *H. pylori* can also cause gastritis, and infected people have two to six times the risk of developing gastric lymphoma and stomach cancer when compared with uninfected people.²⁷

Attention was focused on *H. pylori* among Alaska Native people when it was discovered that anemia caused by blood loss in the stool appeared to be associated with *H. pylori*. High rates of iron deficiency anemia had been observed among Alaska Native people dating back to the 1950s. This led to the discovery that 99% of those with increased fecal blood loss had chronic gastritis caused by *H. pylori*.²⁸

Because of the high rates of gastric cancer in Alaska Native people, and its association with *H. pylori* infection, the CDC Arctic Investigations Program and Alaska Native health organizations are developing studies to better understand gastric cancer in the Alaska Native population and determine if it is associated with *H. pylori* infection in this population.

Goal, Objective & Strategies for Infectious Agents

GOAL: Reduce cancer deaths in Alaska Native people due to infectious agents.

OBJECTIVE PI1: Increase awareness among Alaska Native people of the relationship between certain infectious diseases and cancers.

Baseline: New studies show improvement in areas such as HPV vaccination, *H. pylori* and hepatitis.

Activity a: Promote the use of Human Papillomavirus (HPV) vaccination for cervical cancer prevention through statewide education and outreach campaigns.

Activity b: Monitor emerging science investigating the relationship between infectious agents and cancer.

Endnotes:

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- 4 A Decade of Progress: Tobacco Prevention and Control in Alaska 2010–2011. <http://dhss.alaska.gov/dph/chronic/pages/tobacco/default.aspx>
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SCREENING & EARLY DETECTION

BREAST AND CERVICAL CANCER

The incidence of breast cancer in Alaska Native and U.S. White women is similar at about 128 cases of breast cancer diagnosed per 100,000 women in 2004-2008.¹ The incidence of breast cancer in Alaska Native women ranks first followed by the incidence of colorectal and lung cancer similar to U.S. White women where incidence of breast cancer is also first followed by lung and colorectal cancer.²

There is no significant difference in the breast cancer screening rates of Alaska Native and non-Native women in Alaska. Of the Alaska Native women age 40 years and older, 63% reported receiving a mammogram in the last two years, whereas 69% of non-Native Alaskans reported the same.³ Recent GPRA data indicates 54% of Alaska Native women, age 52-64 years, had a mammogram within the preceding two-year period. The range for mammograms reported by healthcare facilities varied from 15% to 70%.⁴

There is no significant difference in cervical cancer incidence between Alaska Native and U.S. White women. There was also no significant difference between cervical cancer screening rates among Alaska Native and non-Native women (83% vs. 79%).⁵ Recent GPRA data indicates that 68% of Alaska Native women, age 21-64 years, had a cervical cancer screening test within the preceding three-year period. Participating healthcare facilities reported screening range from 46% to 70%.⁶

All seven Alaska Tribal Health System (ATHS) regional hospitals provide mammograms for breast cancer screening (SCF, BBAHC, YKHC, Maniilaq, ASNA, SEARHC, and NSHC). However, availability of mammography services in regional hospitals fluctuates because of workforce changes, availability of certified staff, and equipment status. Itinerant mammography technicians may travel to some hospitals to provide mammograms. Creative attempts to expand mammography availability include: coordination with local hospitals for traveling mammography services, chartering flights from villages to regional facilities for “ladies days” and coordinating breast and cervical screenings with other medical check-ups or procedures.

Five breast and cervical screening programs in Alaska are funded by the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) of the Centers for Disease Control and Prevention (CDC). Four of those are tribal programs at ASNA, SCF, SEARHC and YKHC. The fifth CDC sponsored screening program, Alaska Health Check, is managed by the State of Alaska. These programs offer breast and cervical health screen-

ing services, diagnostic services, case management and access to referral for cancer treatment when necessary. All five NBCCED Programs regularly collaborate with the ANTHC Comprehensive Cancer Control Program and the State of Alaska Comprehensive Cancer Control Program in the Alaska Breast and Cervical Health Partnership. The Partnership maximizes resources by sharing the cost and effort of providing continuing education, patient resources, and educational materials.

Goals, Objectives & Activities for Breast and Cervical Cancer Screening

GOAL: Reduce death from breast and cervical cancer.

OBJECTIVE SB1: Increase the percentage of Alaska Native women aged 40 years and older who receive mammograms every two years to 66% and cervical cancer screenings to 87% by 2017 (Healthy People 2020 targeted a 10% improvement by 2020).

Baseline: 63% of Alaska Native women aged 40 years and older had mammography screening in the previous two years and 83% of Alaska Native women had a cervical cancer screening test done in the previous three years (BRFSS 2008.)

Activity a: Support the development and distribution of health education material for breast and cervical cancer screening.

Activity b: Promote the importance of breast and cervical screening to women through their workplace in businesses with a high proportion of Alaska Native employees.

OBJECTIVE SB2: Maintain collaboration with the Alaska Breast and Cervical Cancer Early Detection Programs through active participation in the Alaska Breast and Cervical Health Partnership through 2017.

Baseline: Collaboration began in 2006.

Activity a: Maintain a Letter of Cooperation with CDC National Breast and Cervical Cancer Early Detection Programs, CDC Colorectal Cancer Screening Programs

and CDC funded Alaska Cancer Registry.

Activity b: Jointly produce at least one patient education resource on breast cancer screening education and awareness annually.

Activity c: Collaborate on one continuing education event for breast and cervical cancer providers annually.

Activity d: Contribute biannually to the Breast and Cervical Health Partnership social media sites and encourage women to use them for breast and cervical screening information and education.

OBJECTIVE SB3: Increase opportunities for tribal breast and cervical cancer programs throughout Alaska to share best practices for screening by 2017.

Baseline: *No organized opportunity for sharing best practices among breast and cervical screening providers in Alaska exists in 2011.*

Activity a: Identify and share practices within NBCCEDP funded programs that can be adapted and used by other breast and cervical screening programs in Alaska.

Activity b: Organize an opportunity for breast and cervical cancer screening programs to network with other breast and cervical programs in Alaska.

COLORECTAL CANCER

Colorectal cancer is the cancer most often diagnosed in Alaska Native men and women. The incidence of colorectal cancer is nearly twice as high in Alaska Native people as it is in U.S. Whites (88/100,000 vs. 45/100,000).⁷ It is the second highest cause of cancer deaths (lung cancer is first for Alaska Native men and women combined).⁸

Colorectal cancer is often treatable when found early through colorectal cancer screening. The ANTHC Cancer Program has focused on increasing education about the need for screening

and supported the Alaska Native Epidemiology Center, the Alaska Native Medical Center, and regional partners in their efforts to increase local capacity for colorectal cancer screening.

Colorectal cancer was identified as one of the top four priorities in the 2005-2010 AHS Cancer Plan. It was also a priority for the State of Alaska Comprehensive Cancer Program. ANTHC and State of Alaska Comprehensive Cancer Programs formed the Alaska Colorectal Cancer Partnership (“CRC Partnership”)

in 2006 to increase public awareness about the disease and encourage colorectal cancer screening statewide. The Alaska CRC Partnership meets monthly and focuses on increasing CRC screening through education and capacity building (equipment, personnel and other resources). The CRC Partnership includes private and tribal physicians, the Alaska Native Epidemiology Center, tribal health organizations, local hospitals, and local and national nonprofit organizations.

The Alaska Native Epidemiology Center is a partner in CRC education, screening, provider training and patient navigation. In 2006 the Epidemiology Center received funds to hire a patient navigator to outreach to family members of people diagnosed with colorectal cancer to encourage CRC screening. Since then the number of patient navigators working to increase CRC screening has increased to more than ten in the state.

In 2009, the CDC Colorectal Cancer Control Program awarded grants to 26 states and four tribal organizations to enhance CRC screening and awareness about colorectal cancer.

Three of the four tribal grants were awarded to Alaska Native programs including the Alaska Native Epidemiology Center, Southcentral Foundation, and the Arctic Slope Native Association. The CRC Partnership collaborates with the Alaskan grantees on education, awareness and screening projects. The Alaska Native Epidemiology Center is working with four or more tribal organizations including SEARHC, Maniilaq Association, BBAHC, and APIA.

Colon Cancer Education Program

Nolan is an inflatable model of a giant colon used by the Cancer Program to educate people statewide about colorectal cancer and the need for screening. The model is large and measures 25 ft long, 12 ft wide and 10 ft tall. Three people can walk side by side through him. In 2011 and 2012 Nolan visited over 25 communities in Alaska with an estimated 5000 visitors.

Nolan the Colon travels to Alaska communities to encourage children and young people to live healthy lives to prevent cancer. He reminds people to be screened for colon cancer at age 50 or sooner if they have a family history of the disease. Colon cancer is the cancer most often diagnosed in Alaska Native men and women. If you would like Nolan to visit your community, contact Judith Muller at jmmuller@anthc.org or (907) 729-4497.



Goals, Objectives & Activities for Colorectal Cancer

GOAL: Reduce the incidence of colorectal cancer.

OBJECTIVE SC1: Increase percentage of Alaska Native people 50 years and older who are screened for colorectal cancer (colonoscopy or flexible sigmoidoscopy) to 80% by 2017 (goal set by the CDC CRC Control Program is 80% by 2014).

Baseline: Colorectal cancer screening rates in Alaska Native people are reported at 50% (BRFSS 2008). More recent GPRA reports indicate colorectal cancer screening rates of 58.5% (GPRA 2012).

Activity a: Provide colorectal cancer awareness and education events in twenty-five tribal health communities including the seven communities who have hospitals with CRC screening capacity to increase screening among Alaska Native people.

Activity b: Use statewide media to increase awareness about colorectal cancer screening.

Activity c: Promote colorectal cancer screening education for Alaska Native men and women through their workplace in businesses with a high proportion of Alaska Native employees.

Activity d: Assist CDC in SECAP II, a survey of the capacity for CRC screening in Alaska including both tribal and non-tribal facilities and providers.

Objective SC2: Maintain Alaska Colorectal Cancer Partnership in conjunction with State of Alaska CCC Program through 2017.

Baseline: Collaboration began in 2006.

Activity a: Collaborate with CDC sponsored Colorectal Cancer Control Programs in Alaska, including regular monthly meetings. Complete two joint projects each year.

Activity b: Support policy and advocacy efforts of the CRC Partnership to increase insurance coverage for CRC screening among self-insured employers.

Activity c: Contribute quarterly to the CRC Partnership social media pages and encourage people to use the pages to access colorectal cancer education resources.

PROSTATE CANCER

Prostate cancer is the most common cancer among men in most populations, but ranks third behind lung and colorectal cancer in Alaska Native men. The average annual age-adjusted prostate cancer incidence rate for the period of 2004-2008 for Alaska Native men was 66 per 100,000 as compared to 153 per 100,000 for U.S. White men.⁹

Two principal methods of screening for prostate cancer are the digital rectal examination (DRE) to identify abnormal modules in the prostate, and the prostate specific antigen (PSA) blood test to identify abnormal antigen levels. PSA levels may be elevated in men who have enlarged or infected prostates or prostate cancer.

In 2008, the U.S. Preventive Services Task Force (USPSTF) concluded that “the current evidence is insufficient to assess the balance of benefits and harms of prostate cancer screening in men younger than age 75 years”.¹⁰ Furthermore, they recommended against screening for prostate cancer in men age 75 years or older. They found evidence that DRE and PSA screening can detect prostate cancer in its early stages, but found mixed and inconclusive evidence that early detection reduces prostate cancer deaths or improves health outcomes.

In fall 2011, the USPSTF concludes that there is moderate certainty that the benefits of PSA-based screening for prostate cancer do not outweigh the harms. Therefore, the USPSTF recommends against prostate-specific antigen (PSA)-based screening for prostate cancer (D recommendation).¹¹

The National Cancer Institute (NCI) has not made screening recommendations or issued screening guidelines. In addition to lack of evidence that PSA screening reduces deaths from prostate cancer, there is evidence that treatment of prostate cancers can cause significant, adverse and undesirable outcomes. At this time some physicians in the ATHS do not routinely recommend that men without symptoms be screened for prostate cancer using the PSA test.

Goals, Objectives & Activities for Prostate Cancer

GOAL: Increase informed decision making regarding prostate screening among Alaska Native men.

OBJECTIVE SP1: Understand current practices among primary care clinicians in the ATHS with regard to prostate screening and patient care by 2017.

Baseline: Limited information is available about current practices in prostate screening in ATHS in 2010.

Activity a: Survey primary care clinicians in the ATHS to better understand attitudes toward and practices surrounding prostate cancer screening, follow-up and survivor care.

Activity b: Provide primary care providers with the latest information regarding recommendations for prostate screening.

OBJECTIVE SP2: Develop and distribute educational material to Alaska Native men and their health care providers regarding prostate screening recommendations by 2017.

Baseline: Limited prostate screening educational materials specific to Alaska Native men are available in 2010.

Activity a: Develop patient information materials on informed decision making for Alaska Native men.

Activity b: Distribute materials throughout the ATHS.

OBJECTIVE SP3: Develop and participate in activities designed to support prostate and testicular cancer survivors by 2017.

Baseline: Few activities centered on prostate and testicular cancer education are available to Alaska Native men.

Activity a: Organize annual Men's Retreats for prostate and testicular cancer survivors emphasizing the importance of continued routine prostate screenings.

Activity b: Support activities of the Alaska Prostate Cancer Coalition.

Activity c: Support the State of Alaska CCC Program in a survey of prostate cancer survivors to better understand the needs of men in Alaska.

EMERGING SCIENCE

New methods and recommendations for screening are regularly evaluated by medical staff. The ANTHC Cancer Program promotes continuing education for oncology clinic physicians and nurses at professional meetings and conferences.

Mayo Cancer Clinic (MCC) annually provides updates on emerging science at a joint Mayo/ANMC Cancer Conference. Professionals from MCC present on their area of expertise. These conferences are financially supported by MCC. Topics are identified by ANMC and ANTHC providers and program managers.

Goals, Objectives & Activities for Emerging Science

GOAL: Investigate the availability and appropriateness of new tests and procedures to prevent, detect, diagnose, and treat cancer survivors and those receiving palliative care and incorporate them in the cancer program.

OBJECTIVE SO1: Educate and promote new cancer screening and early detection tests as recommended by national organizations by 2017.

Baseline: No formal tracking system of new screening tests exists in 2010.

Activity a: Assist Mayo Cancer Center in organizing an annual cancer conference at ANMC.

Activity b: Review literature to identify state of the art cancer screening opportunities for Alaska Native people.

Activity c: Monitor outcomes of Alaska Native Epidemiology Center research on fecal immunochemical testing (FIT) and stool DNA testing for Alaska Native people.

Endnotes:

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DIAGNOSIS & TREATMENT

DIAGNOSIS

More than 400 cases of cancer are diagnosed each year in Alaska Native people.¹ Approximately 80% of all Alaska Native people diagnosed with cancer receive some cancer care at the Alaska Native Medical Center (ANMC) in Anchorage. The most frequently diagnosed cancers for Alaska Native people during 2004-2008 were colon/rectum, lung and breast cancers. Together, these three types of cancer comprise half of all new cancer diagnoses.²

Confirming or ruling out a cancer diagnosis may take several weeks or months. Many tests and procedures may be necessary to determine a diagnosis. A combination of radiology, pathology and surgery services is typically used to diagnose cancer, determine the stage of the cancer, and design a treatment plan. Some diagnostic surgical procedures, such as biopsies and colonoscopies, can be done at the six regional hospitals and contracted facilities, with patients then referred to ANMC with a confirmed or suspected cancer diagnosis for additional evaluation. ANMC uses nationally recognized diagnostic procedures to diagnose and confirm cancer. Expert reference laboratories outside Alaska may be used to confirm a diagnosis.

TREATMENT

Cancer treatment generally involves one or a combination of treatments including surgery, radiation, chemotherapy, immunotherapy, and hormonal therapy. For some cancers, only surgery is needed. For others, a combination of two and sometimes three treatments are needed. The patient's physician, with consultation from other physicians, develops a treatment plan based on the type and stage of cancer, the patient's overall physical health and recommended treatment plans in accordance with national guidelines such as the Comprehensive Cancer Center Network (NCCN) guidelines. The treatment plan designed for each patient offers the best chance of long-term survival.

Cancer surgery is primarily done by ANMC physicians. Radiation therapy is done at centers in Anchorage, Wasilla/Palmer and Fairbanks. Chemotherapy is performed primarily in the Hematology/Oncology Clinic and in rare instances some regional hospitals. Immunotherapy, antibody and hormone therapies are also provided at the ANMC Infusion Center.

Cancer treatment changes frequently. Research findings, new drugs and clinical trials provide new ways to treat patients, reduce side effects, and increase survival rates. Advances in surgery have resulted in less invasive surgery including smaller inci-

sions and shorter recovery time. Some of these advances result in increased use of outpatient services and shortened hospital stays. Longer survival also creates a need for additional services, routine cancer care follow-up and cancer survivorship services. The most up-to-date cancer treatment recommendations are monitored by ANMC Hematologists/Oncologists and other medical staff. When available and appropriate, new treatments are offered to cancer patients.

Treatment Team

Cancer treatment takes more than the patient and one doctor. It requires an interdisciplinary team approach that may include the patient, family, multiple physician specialists, nurses, nutritionists, social workers, radiology and laboratory staff, community health aides/practitioners and many others.

ANMC staff includes experienced general and sub-specialty surgeons who provide cancer surgery and follow-up care to cancer patients. Board certified Hematologists and Oncologists practice in the ANMC Oncology Clinic as well as a well-trained nursing and support staff. The ANMC medical staff also provides consultative support to physicians at the six regional hospitals when a patient returns home.

In the regional hospitals there are few nurses trained to administer chemotherapy and critical care support to treat life threatening infusion reactions is limited. If trained nursing positions are vacant (and the turnover rate of health care professionals working in remote hospitals is high), patients must travel to ANMC for chemotherapy until other nurses are trained. One ANMC Oncology Clinic nurse is certified to provide oncology chemotherapy and biotherapy courses to regional hospital nursing staff. This training allows regional hospital nurses to administer chemotherapy with the treatment plan developed at ANMC and allows some patients to receive treatment closer to home.

Children with Cancer

Compared with adult cancers, childhood cancers are rare. In the United States they make up about 1% of all cancers. The rate among all Alaska Native children for all cancers combined is similar to U.S. Whites. When cancer is suspected in Alaska Native children, care is coordinated between ANMC and Providence Hospital's Pediatric Oncologists. Treatment for some pediatric cancers requires travel to out-of-state cancer centers.

Clinical Trials

Clinical trials are research studies in which people help doctors

find ways to improve health and cancer care. Each study tries to answer scientific questions and to find better ways to prevent, diagnose, or treat cancer.

A clinical trial is one of the final stages of a long and careful cancer research process. Studies are done with cancer patients to find out whether promising approaches to cancer prevention, diagnosis, and treatment are safe and effective. Acceptance into a clinical trial is dependent on many factors including the type of cancer, condition of the patient and availability of the needed clinical trials. If participants do not benefit directly, they still make an important contribution to medicine by helping researchers better understand the disease to help future generations.

There are five different types of clinical trials:

- Treatment trials test new treatments such as a new cancer drug, new approach to surgery or radiation therapy, new combinations of treatments, or new methods such as gene therapy.
- Prevention trials test new approaches like medicines, vitamins, minerals, or other supplements that doctors believe may lower the risk of a certain type of cancer. These trials look for the best way to prevent cancer in people who have never had cancer or to prevent cancer from coming back or a new cancer occurring in people who have already had cancer.
- Screening trials seek to find new ways of detecting cancer in people before they have any symptoms.
- Diagnostic trials seek to find how new tests or procedures can identify cancer more accurately and at an earlier stage.
- Quality of Life trials (also called Supportive Care trials) explore ways to improve comfort and quality of life for cancer patients.

Diagnosing and treating cancer

From the time cancer is suspected to the time treatment begins can take days, weeks and sometimes months. Why does it take so long to diagnose cancer? There are over 300 types of cancer. To diagnose or rule out cancer, special doctors called pathologists must look closely at suspected cancer cells under microscopes. They may need to see more cells and so a patient must have another surgery to take more tissue samples. Sometimes doctors are still not sure if it is cancer and so sends out tissue samples to other laboratories who are national experts to help determine the diagnosis. Patients must have several tests over time to see if cancer is present and where it might have spread to. Once cancer is diagnosed, a treatment plan is developed. Why is it so hard to treat cancer? Each cancer behaves differently in every person. There are some national guidelines that provide suggestions on how to treat specific cancers, but each individual may respond differently to the suggested treatment. The oncologist develops a treatment plan based on national standards, but also looks carefully at each person to figure out the best way to treat cancer. This can take several days or sometimes weeks.

Goals, Objectives & Activities for Diagnosis and Treatment

GOAL: To diagnose cancer as early as possible using the least invasive and most comprehensive procedures available. When cancer is diagnosed, treat the patient and family with the most appropriate therapy as close to home as possible.

OBJECTIVE DT1: Support efforts to achieve state of the art diagnostic and treatment services at ANMC and at specialty and field clinics by 2017.

Baseline: Recognized need in to monitor and support new diagnostic and treatment services in 2010.

Activity a: Partner with ANMC Cancer Committee to identify and support cancer diagnostic and treatment services.

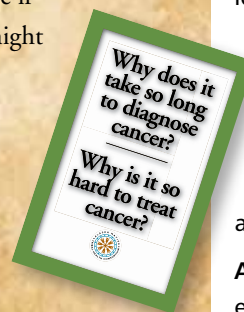
Activity b: Support state and national efforts to reduce cancer drug shortages.

Activity c: Develop patient education materials which explain diagnostic and treatment procedures and helps patients understand the process of making a cancer diagnosis and developing a treatment plan.

Activity d: Investigate the use of a standard oncology formulary throughout the ATHS.

OBJECTIVE DT2: Increase the number of ANMC and ATHS oncology nurses certified by the Oncology Nursing Society (ONS) to six by 2017.

Baseline: Four nurses within the ATHS are certified in 2010. Eighty-six nurses have been trained to deliver



chemotherapy since 2006 (ANMC Oncology Clinic 2011).

Activity a: Identify and support ANMC oncology nurses interested in becoming ONS certified.

Activity b: Support chemotherapy instruction training and the efforts of nurses in regional facilities to provide chemotherapy.

OBJECTIVE DT3: Coordinate cancer patient navigation services at ANMC, regions and communities to ensure timely and efficient cancer care coordination by 2017.

Baseline: Cancer patient navigation services are limited in the AHS in 2010. The Oncology Social Worker (new position since 2005) and Oncology Clinic case management staff currently provide this service at ANMC.

Activity a: Identify collaborative and financial means to support establishing a coordinated cancer patient navigation program.

Activity b: Develop patient education materials applicable to diagnosis and treatment.

Activity c: Support the development of paper end-of-treatment summaries for cancer patients with electronic health records system until the EHR component is available at ANMC.

OBJECTIVE DT4: Establish a pain and symptom management program to ensure that cancer patients receive timely and effective pain and

symptom therapy regardless of whether they are treated at ANMC, regional hospitals, or villages by 2017.

Baseline: There is no comprehensive, integrated cancer pain and symptom program in the AHS in 2010.

Activity a: Collaborate with ANMC Pharmacy, palliative care providers, and others to establish a pain and symptom management program including better access to medications throughout the AHS.

Activity b: Use findings from 2010 patient self-identification of symptoms project to better coordinate with regional and village healthcare providers.

OBJECTIVE DT5: Implement a clinical trials plan at ANMC by 2017.

Baseline: Clinical trials are not available at ANMC in 2010.

Activity a: Develop clinical trials communication plan

Activity b: Develop patient and community education materials explaining clinical trials.

Activity c: Develop and support policy changes necessary to offer clinical trials.

Endnotes:

1 Alaska Native Tumor Registry, 2004- 2008

2 Ibid.



Photo © Clark James Mishler

SURVIVORSHIP

Calculations of cancer survival, 1992-2002, show that among Alaska Native patients diagnosed with cancer, less than half (49%) will be alive five years after diagnosis. A larger percent of women (57%) than men (40%) survived five years after their cancer diagnosis.¹

Comparison of Alaska Native and U.S. White five-year survival rates, 1992-2002, show that for all cancers combined, Alaska Native men and women had a 17% lower five-year survival rate.² The lower overall survival rate of Alaska Native people is due in part to the types of cancer that occur more frequently among Alaska Native people. Cancers of the esophagus, pancreas, lung, gallbladder, and nasopharynx have low survival rates in all populations, and account for a greater percentage of cancers diagnosed among Alaska Native people and later diagnosis stage. For example, cancer of the nasopharynx is 19 times more likely to occur in Alaska Native people than in U.S. Whites, and cancer of the gallbladder is five times more likely to occur in Alaska Native people than in U.S. Whites.³ For breast, stomach, prostate and cervical cancers, Alaska Native survival rates were similar to U.S. Whites. For two sites, liver and uterus, Alaska Native people are more likely than U.S. Whites to survive five years.⁴

Advances in the prevention, early detection, diagnosis, and treatment of cancer help cancer patients live longer. As a result, there is a growing population of cancer patients who have survived five years or longer with a cancer diagnosis, and a new focus on the complications of both cancer and its treatment. Part of the focus is on physical, social, and mental challenges encountered by survivors over the near and long term following cancer diagnosis and the practical daily issues of living with cancer or chronic side effects after cancer treatment.

Cancer survivorship is a continuum that begins with diagnosis and continues through the remainder of life. Cancer survivors face a myriad of concerns, including the fear of a cancer recurrence, increased risk of a second cancer, late appearing side effects resulting from treatment, fatigue, cognitive problems, sexual dysfunction or fertility problems, changes in family roles and daily activities, financial impact of cancer treatment, employment issues and disability.

Vast distances, remote rural communities, difficult access to health care providers, and differences in language and culture influence the care and support of survivors in Alaska. The challenge of survivorship is to assist the patient and family through the stages of cancer, the diagnosis and treatment process, the post treatment check-ups, and the period of rehabilitation and a “new normal” after cancer treatment.

There can be communication misunderstandings between health care providers, families, and the patient. When cultural and language differences exist, a patient’s concerns often go unasked and fears unresolved. The need for easier ways to navigate the treatment system and better understand the resources available to cancer survivors exists at all levels of care.

Living longer after a diagnosis of cancer is an important outcome of cancer treatment. However, it also means more cancer patients need continued medical follow-up. In the ATHS, this type of medical care for survivors is the responsibility of primary care providers with appointments with cancer specialists as recommended.

ANTHC programs and resources for survivors developed through the Cancer Program over the past five years include a Traditional Food Guide for Alaska Native Cancer Survivors, the Men’s Retreat for Prostate and Testicular Cancer Survivors, Camp Coho for children who have lost a loved one to cancer, and an ongoing cancer survivor support group offered weekly at the Alaska Native Medical Center. Rural sites with support groups can link to presentations on topics for survivors available through ANMC and partner organizations. Program staff participates in a statewide Survivorship Committee that organizes activities and an annual conference on this topic for patients and providers.

Goal, Objectives & Activities for Survivorship

GOAL: Alaska Native cancer patients and their families will have access to programs and services that address their physical, mental, spiritual and practical needs to improve the length and quality of life.

Objective SS1: Develop a comprehensive Survivorship Plan for the ATHS to guide the development of new programs and services for cancer survivors. The plan will support cancer survivors and address their physical, mental, spiritual, and practical concerns by 2017.

Baseline: *There is no Survivorship Plan for Alaska Native cancer survivors in 2010.*

Activity a: Perform a needs assessment of Alaska Native cancer survivors.

Activity b: Identify gaps in existing cancer survivorship programs within the ATHS and prioritize needed

resources and programs.

Activity c: Determine provider knowledge regarding survivor issues.

Activity d: Complete a comprehensive five year Survivorship Plan for ATHS.

Activity e: Support the development of two resources identified in the Survivorship Plan.

Activity f: Develop a resource plan to anticipate funding needed to support survivorship efforts in the future.

OBJECTIVE SS2: Enhance clinical care management and follow-up care for patients diagnosed with cancer to minimize recurrences, detect secondary cancers early, and ensure maximum years of quality of life by 2017.

Baseline: A comprehensive program for providing follow-up care to patients at the end of cancer treatment does not exist within the ATHS in 2010.

Activity a: Complete a paper end of cancer treatment summary for each cancer patient and incorporate it into ATHS electronic medical record systems.

Activity b: Develop a tracking system to identify survivors and standardize recommended early detection and screening recommendations.

Activity c: Increase educational opportunities for providers on new clinical practices addressing survivorship issues.

OBJECTIVE SS3: Encourage and support the delivery of established survivorship programs by regional tribal health organizations by 2017.

Baseline: ANTHC has established survivorship programs that can now be adopted by regional tribal health organizations.

Activity a: Support at least two Men's Retreats for Cancer Survivors organized in regions.

Activity b: Support at least two Camp Coho events.

Activity c: Encourage and support the development of community based support groups working with patients and families of survivors to provide assistance to cancer patients returning home after cancer treatment.

Activity d: Support training for six individuals willing to facilitate regional cancer support groups.

Activity e: Review and revise Traditional Food Guide for Alaska Native Cancer Survivors published in 2008.

Activity f: Coordinate with the ANTHC Behavioral Health Aide (BHA) Program to include training for Aides on the emotional and psychological needs of cancer survivors.

Men's Retreat for Prostate and Testicular Cancer Survivors

For men who have been diagnosed with prostate or testicular cancer, survivorship is often complicated by treatment side effects that challenge a man's physical, mental and social well-being. Despite the proven effectiveness of support groups at reducing depression in cancer patients, men typically do not participate in them.

Since 2009, the Cancer Program has offered a Men's Retreat for Prostate and Testicular Cancer Survivors. The Retreat is a two-day event that brings together survivors from across the state in a supportive environment to discuss and share their experiences. Each Retreat includes an activity choice of fishing, hiking or rafting if available.

ANTHC and the SouthEast Alaska Regional Health Consortium (SEARHC) partnered to offer the first Men's Survivorship Retreat on Prince of Wales Island in May 2011 followed by one in 2012. ANTHC provided technical assistance to SEARHC in the planning and coordination of the event.

Technical assistance is available for those who would like to host a Men's Retreat in their region. For more information, contact Stacy Kelley at sfkelley@anthc.org or (907) 729-2927.



Endnotes:

- 1 Cancer in Alaska Native people 1969-2003: 35 Year Report: Office of Alaska Native Health Research and Alaska Native Epidemiology Center, Alaska Native Tribal Health Consortium, January 2006.
- 2 Ibid.
- 3 Ibid.
- 4 Alaska Native Cancer Survival Report, 1984-1994, Lanier A, Holck P, Kelly J, et.al. April 1999.

PALLIATIVE CARE

Palliative care is the total care of the body, mind, and spirit of the patient and family. The purpose of palliative care is to prevent or lessen the severity of pain and other symptoms and to achieve the best quality of life for people diagnosed with a chronic disease such as cancer.

The goal of palliative care is to achieve the best possible quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of illness in conjunction with cancer treatment.

Alaska Tribal Health System (ATHS) and Palliative Care

Care for elders and those with life limiting diseases, especially for those who live in rural Alaska, is challenging. As documented in several surveys completed as part of the NCI Palliative Care Education grant¹ and in provider, patient and family conversations, most patients wish to go home or as close to home as possible to spend the last part of life with families and friends in familiar surroundings.

The first formal Palliative Care Program in the ATHS was established in Bristol Bay in 1999 with the assistance of and funding by the Robert Wood Johnson Foundation (RWJ) Excellence in End of Life Care Program.² Because of the high cost of, and difficulties encountered in trying to deliver end-of-life care services to remote communities, a village-focused volunteer and primary care program was developed that combined a regionally-based physician and home health nurse to deliver integrated palliative care.

The five year (2005-2009) NCI Palliative Education Grant awarded to the ANTHC Research and Clinical Services program was designed to improve palliative education and change practice patterns to minimize non-acute deaths at the Alaska Native Medical Center (ANMC) and other ATHS health facilities as well as increase implementation of palliative care measures.³

2011 palliative care resources in the ATHS are limited.

Examples of available services in five regions include:

- Kodiak Area Native Association -- nurse and social worker navigators
- Tanana Chiefs Conference (Fairbanks area) -- nurse and social worker navigators. The nurse visits each elder once a year
- Southcentral Foundation (Anchorage area) -- home-based healthcare program
- Norton Sound Health Corporation -- small facility for patients to stay as end of life nears.

- Bristol Bay Area Health Corporation -- nurse support
- Yukon Kuskokwim Health Corporation -- case by case basis; some home visitation in Bethel by physicians.

Other Palliative Care Programs in Alaska

Providence Alaska Medical Center (PAMC) has the only palliative care consultative program in Alaska. The PAMC program provides primarily in-hospital services. The program offers approximately 5,600 consults per year with an in-hospital population ranging from 8-14 patients.

Pediatric Palliative Care

Currently, there is no pediatric palliative care program in Alaska. The Palliative Care Consultation Program at PAMC is planning to offer a Pediatric Palliative Care Symposium and support pediatricians as much as possible in their efforts to become board certified in palliative care.

ANMC will work with the PAMC Palliative Care Consultative Team, the Oregon Health and Sciences University (OHSU), and Seattle Children's Hospital Pediatric Palliative Care Program to help make certain that Alaska Native pediatric patients have access to experienced palliative care providers. Video conferencing (VTC) capability expands the opportunity for palliative care consultation and connecting families and patients. The goal will be to provide medical and palliative care to children as close to home as possible.

Hospice

PAMC Hospice is the only Medicare certified hospice in Anchorage. Additional Medicare certified hospices are located in Wasilla and Juneau. The Hospice of Anchorage no longer provides 24 hour nursing support but works in consultative and grief support roles. Volunteer hospices providing Various levels of services are located in Anchorage, Homer, Haines, Soldotna, Fairbanks and Ketchikan. There is no Hospice House in Alaska.⁴

The ANMC Palliative Care Program will be based on the consultative model. The palliative care consultation team will work with the patient's physician and provide consultation as to the best approach/need for palliative care including pain and symptom management. Additional support may be provided when patients are discharged from the hospital, with the emphasis on reducing Medevacs, Emergency Department (ED) visits and/or inpatient and Intensive Care Unit (ICU) admissions. The team will also support the patient and family's wishes if they choose to return home or as close to home as possible. The team will provide consultative support for chronic disease patients diagnosed

in advanced stages of disease. Ideally, all patients diagnosed with an initial chronic disease such as cancer will have a palliative care consultation as treatment begins.

Goals, Objectives & Activities for Palliative Care

GOAL: Provide active total care of the body, mind and spirit of a patient and family and to help the patient achieve the best quality of life possible as close to home as possible.

OBJECTIVE PC1: Develop and implement a Palliative Care Program at ANMC for appropriate outpatient clinics and inpatients by 2017.

Baseline: A palliative care program does not exist at ANMC.

Activity a: Identify needed resources and secure support for palliative care consultant team

Activity b: Develop policies and procedures manual for integration of Palliative Care Program into ANMC quality of care and other essential programs.

Activity c: Design regional and community program access guidelines.

Activity d: Conduct an International Telehealth Palliative Care Symposium annually or as funding is available.

OBJECTIVE PC2: Establish remote Palliative Care Consultation Program component by 2017

Baseline: A remote Palliative Care Consultation Program does not exist in 2011.

Activity a: Identify resources needed to support the following and implement as feasible:

- Registered nurse to return with patient to home community after discharge from ANMC for initial patient/family teaching and home setting evaluation.

- With recommendations from regional and community healthcare providers, determine the type and level of palliative care consultation support needed to support patients and providers in the regional hospital setting and home communities.
- Utilize ANTHC Telehealth program to coordinate consultations with providers, patients, families and communities at regional hospitals, CHAP clinics and

patient homes to optimize patient/family quality of life, reduction of signs and symptoms and reduced travel.

Activity b: Establish ATHS-wide palliative care formulary.

OBJECTIVE PC3: Determine need for and feasibility of establishing hospice programs by 2017

Baseline: There are no volunteer or Medicare-certified hospices for remote communities in Alaska in 2011.

Activity a: Monitor third party reimbursement and policy changes for palliative/hospice care.

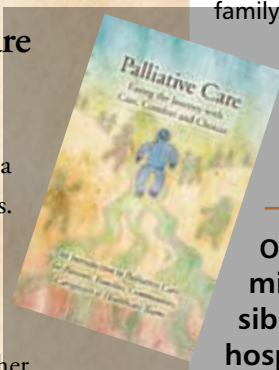
Activity b: Educate legislators, healthcare providers and communities about the need to support community-based palliative care/hospice programs.

Endnotes:

- 1 NCI Palliative Education for Healthcare Providers of Alaska Native people. Provider surveys, 2005, 2007. Community Health Aide/Practitioner survey 2006.
- 2 DeCourtney, Christine A. MPA, Kristina Jones, RN, MPH, Melanie Merriman, Ph.D, 2010. Nina Heavener, RN, BSN, P. Kay Branch, MA. Establishing a Culturally Sensitive Palliative Care Program in Rural Alaska Native American Communities. Journal of Palliative Medicine. Vol. 6, No. 3, June 2003, p. 501.
- 3 Evaluation: Changes in provider practice and utilization. Melanie P. Merriman, PhD, MBA, 2010. The Center to Advance Palliative Care (CAPC) provides health care professionals with the tools, training and technical assistance necessary to start and sustain successful Palliative Care Programs in hospitals and other health care settings. CAPC is a national organization dedicated to increasing the availability of quality palliative care services for people facing serious illness. DeCourtney, Christine A., MPA, Branch, P. Kay, MA, Morgan, Karen M, B.A. Gathering Information Through Qualitative Research to Develop Palliative Care for Alaska's Aboriginal People, Journal of Canadian Palliative Care, Vol 26, (1) January 2010, 22-31.
- 4 At the present time, there is no Medicare-certified hospice for remote communities. The health care services are too limited to meet Medicare hospice requirements. However, with the tax reform law and the Indian Health Service (IHS) recognition of the need for long term care services, there may be an opportunity to identify demonstration funding and develop a hospice program for remote communities utilizing telehealth and alternative resources.

Palliative Care

When someone is diagnosed with a disease like cancer, a long journey begins. While a patient's body is treated and cared for to reduce pain and other symptoms, it is also important to care for the whole person at all steps of the disease journey. Palliative care pays attention to the mind, body and spirit of the patient and family. It begins with the diagnosis of a life-limiting disease. Palliative care is about living, not about dying. Palliative Care, Easing the Journey with Care, Comfort and Choices is an introduction to palliative care for patients, families, communities, caregivers and healthcare teams. It provides suggestions for what patients, families and friends can do to help make the cancer journey easier. For a copy of the 35 page booklet contact Christine DeCourtney at cdcourtney@anthc.org or (907) 729-3922



SURVEILLANCE & RESEARCH

In order to make informed decisions on how to best use resources to address the cancer burden among Alaska Native people, it is important to have accurate and timely data. The term “surveillance” is used to describe the systematic collection, analysis, and interpretation of health data for planning, implementing, and evaluating health programs. All aspects of the Comprehensive Cancer Program, from defining the burden of cancer and guiding planning activities to monitoring changes and evaluating intervention efforts, rely upon the availability of strong and relevant surveillance activities.

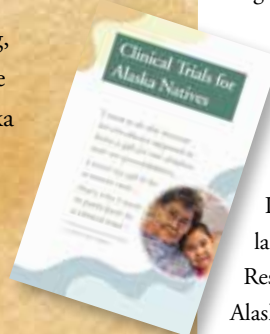
In surveillance, data is gathered on the occurrence of cancer (incidence), cancer deaths (mortality), risk factors for the development of cancer (tobacco use, overweight, fruit and vegetable intake), cancer screening activities (use of mammography, colonoscopy, Pap tests), and the use of diagnostic and treatment services. Timely and high quality data are ideally transformed into information that is easily accessible to those who use it to prevent, control, and research cancer.

In the Alaska Tribal Health System (ATHS), cancer surveillance provides important data for use in:

- Identifying people at an increased cancer risk who would benefit from Cancer Control interventions.
- Describing and monitoring cancer trends so that appropriate and timely interventions can be made.
- Planning and evaluating cancer and educational programs.
- Planning for future needs for diagnostic and treatment services (hospital beds, physician and nurse staffing, outpatient

Clinical Trials and Research

Despite implementation of nationally recommended cancer screening and treatment guidelines, survival from the disease has not increased significantly among the Alaska Native population. Existing barriers to research among Alaska Native people include a lack of trust of interventional research resulting from prior exposure to unethical practices; limited infrastructure, and a mistrust of “helicopter research” in which outside investigators collect data and then leave the community without ever reporting their findings. Nationwide, only 3% to 5% of cancer patients participate in cancer clinical trials. Among those who participate, only 0.5% self-report Native American heritage. Nationally-recommended cancer prevention, screening, and treatment modalities are mostly untested in the Alaska Native population before they are implemented as standard of care. Increasing participation in cancer research and clinical trials by the Alaska Native people will increase the likelihood of identifying better ways to treat cancer in the Alaska Native population. ANTHC is moving forward by developing partnerships with nationally recognized cancer programs like the Mayo Cancer Center to increase research opportunities to prevent, screen, diagnose and develop the best treatment options for the Alaska Native people.



surgery and chemotherapy services, and rehabilitative and home care).

- Investigating public concerns about suspected high numbers of cancer diagnosis.
- Providing data to raise awareness of public health problems and support the development of policies.
- Conducting and advancing research related to the cause, prevention, and treatment of cancer.

Cancer surveillance is supported by data from a variety of sources including the Alaska Native Tumor Registry (ANTR), the Alaska Cancer Registry (ACR), the Alaska Native Medical Center Cancer Registry, the Alaska Behavioral Risk Factor Surveillance System (BRFSS), Healthy People 2020 (HP 2020), Pregnancy Risk Assessment Monitoring System (PRAMS), Youth Risk Behavior Survey (YRBS), the Government Performance and Results Act (GPRA), the National Cancer Institute (NCI), and the Surveillance, Epidemiology, and End Results Program (SEER). State of Alaska and U.S. databases are useful for comparing Alaska Native data with other populations in the state or nation.

Research

The ANTHC Cancer Program is part of the Department of Clinical and Research Services, Division of Community Health Services. The department identifies health research needs and priorities, enhances capacity to conduct research, increases participation of Alaska Native people

in the conduct of health research, pursues funds for conducting research projects, develops a database of health research involving Alaska Native people, promotes communication of research

findings in the scientific literature as well as to the participating communities, and coordinates all research within ANTHC. In addition to research activities, the department supports the HIV and Hepatitis clinical services, the Comprehensive Cancer Control program, and the Immunization program.

Clinical Trials

One major component of a comprehensive cancer program not currently available at ANMC is access to investigational therapies through participation in clinical trials. There is increasing evidence of improved patient outcomes from participation in clinical trials compared with noninvolved patients diagnosed with non-small-cell lung, breast, colorectal, and testicular cancer. Due, in part, to lack of American Indian/Alaska Native participation in clinical trials, little is known about the impact of specific chemotherapy drugs on this population. In 2011, ANMC approved a plan to implement a clinical trials program, which will be available for Alaska Native patients in 2012. While the impact of ANMC participation in clinical trials will not be known for many years, it is hoped that the results will be useful in helping determine the impact of chemotherapy drugs on American Indian/Alaska Native people. Developing clinical trial opportunities at ANMC will help reduce barriers to Alaska Native volunteer participation in clinical trials. Innovative and culturally appropriate patient information and education will help increase tribal leadership, provider, patient, family and community understanding about the importance of being involved in a clinical trial.

Goal, Objective & Strategies for Surveillance and Research

GOAL: Utilize complete, accurate, and timely data on cancer in Alaska Native people to

provide the basis for cancer programs and services.

OBJECTIVE SR1: Support the gathering and maintenance of data systems to understand the cancer related needs of Alaska Native people through 2017

Baseline: *The Alaska Native Tumor Registry provides data for use in cancer research and program planning and implementation in 2011.*

Activity a: Support the efforts of the Alaska Native Tumor Registry to continue to gather and report cancer data on Alaska Native people.

Activity b: Develop and implement communications plan to inform and educate Alaska Native people and providers of the importance of clinical trials.

Activity c: Support the development of cancer clinical trials at ANMC and ANTHC.

Activity d: Maintain ongoing review of research outcomes to improve cancer prevention and care.

Objective SR2: Promote an understanding of cancer data among Alaska Native people.

Baseline: *The Cancer Program has limited methods of explaining cancer data that also engages community in behaviors and activities that influence that data.*

Activity a: Support efforts in health literacy and understanding of cancer data.

Activity b: Develop a booklet that includes examples of cancer data and suggests ways that an individual, family or community can influence the data.



Kaktovik, Photo by Karen M. Morgan

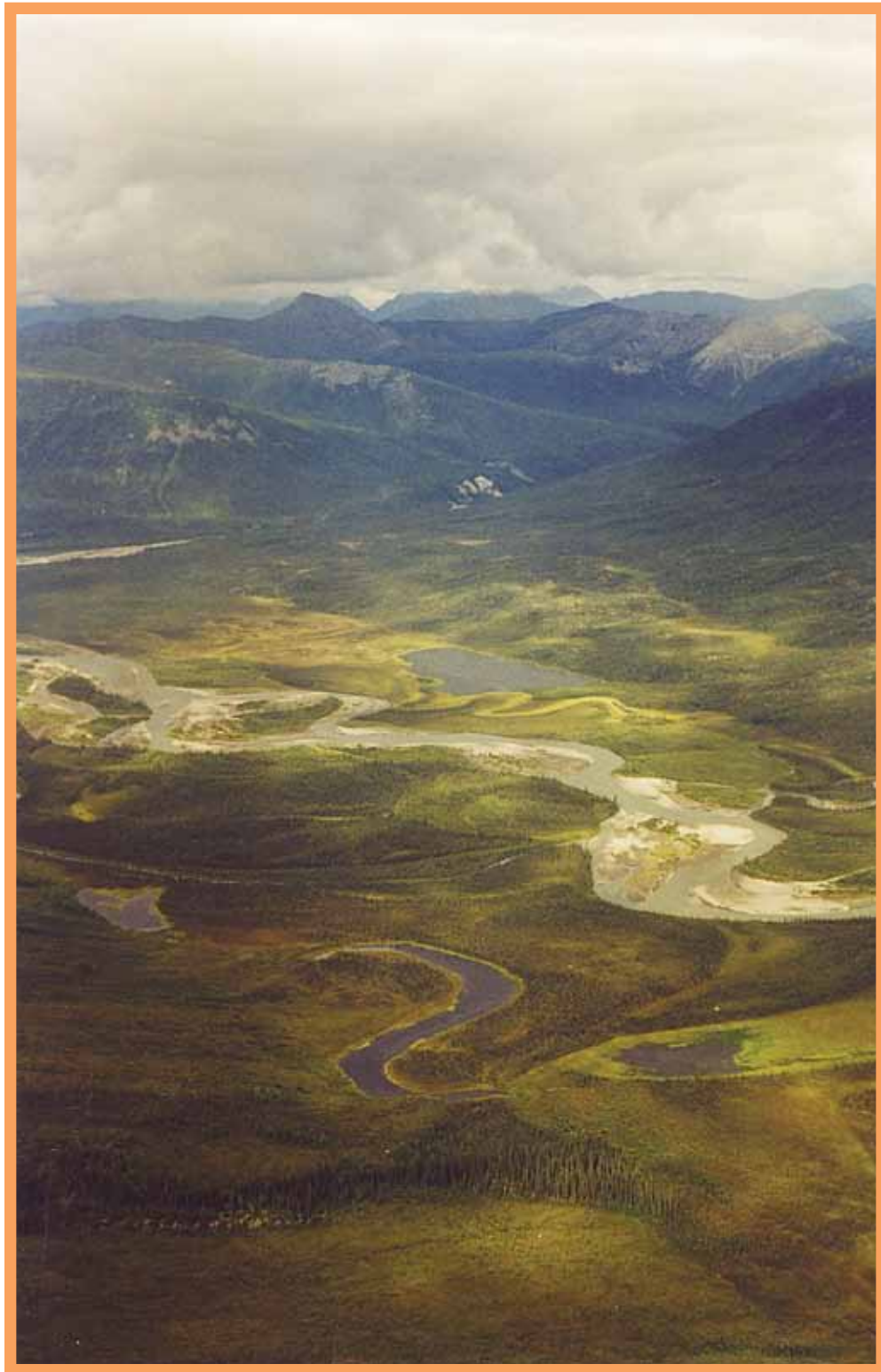


Photo by Brian Adams

APPENDIX I

Alaska Tribal Health System Comprehensive Cancer Plan Goals, Objectives & Strategies

Chapter 2 PREVENTION

Tobacco Use

Goals, Objectives & Strategies for Tobacco Use Prevention

GOAL: Reduce cancer incidence, illness, and death due to tobacco use among Alaska Native people.

OBJECTIVE PT1: Expand and develop the ATHS capacity to address tobacco dependence by incorporating tobacco control systems in twelve tribal organizations by 2017.

Baseline: Nine tribal organizations have incorporated tobacco control systems in 2011 (ANTHC Tobacco Program)

Activity a: Educate policy decision makers to increase funding for tobacco control programs in Alaska.

Activity b: Support state funding to encourage systemic, sustainable change to reduce tobacco-related illness and death.

Activity c: Coordinate with tobacco partners and other chronic disease programs to implement evidence-based brief interventions and tobacco systems

Activity d: Coordinate with the State of Alaska Quit Line to expand the number of healthcare providers who have access to cessation services.

Activity e: Investigate using a standard Nicotine Replacement Therapy (NRT) formulary throughout the ATHS.

OBJECTIVE PT2: Increase the number of patients enrolled in ATHS tobacco treatment by 25% by 2017.

Baseline: 11,753 enrollees in 2011 (ANTHC Tobacco Treatment Database)

Activity a: Expand the number of health care providers offering tobacco treatment.

Activity b: Improve systems by which a health care provider can refer patients to tobacco treatment.

OBJECTIVE PT3: Increase the percentage of Alaska Native patients screened for tobacco use in ATHS health care facilities to 75% by 2017.

Baseline: 61% (GPRA 2010)

Activity a: Expand tobacco cessation knowledge and application of the "5A's" (Ask, Advise, Assess, Assist, and Arrange) by offering ongoing training to ATHS providers.

Activity b: Improve systems to remind health care provider to ask each patient at each visit if they use tobacco and determine their readiness to quit and advise them accordingly, based on the USPHS Clinical Practice Guidelines.

OBJECTIVE PT4: Reduce the percentage of adult Alaska Native smokers to 33% by 2017.

Baseline: 36% (BRFSS 2011)

Activity a: Ensure that all Alaska Native people who wish to quit tobacco have access to evidence based cessation interventions.

Activity b: Increase Alaska Native specific tobacco control initiatives to assure comprehensive, culturally appropriate media messages reach the intended audience.

Activity c: Support advocacy efforts to pass a statewide clean indoor air policy and increase tobacco taxes.

OBJECTIVE PT5: Reduce the percentage of adult Alaska Native spit tobacco users to 10% by 2017.

Baseline: 16% (BRFSS 2010)

Activity a: Ensure that all Alaska Native people who wish to quit spit tobacco have access to evidence based cessation interventions.

Activity b: Increase Alaska Native specific spit tobacco control initiatives to assure comprehensive, culturally appropriate media messages reach the intended audience.

Activity c: Support advocacy efforts to pass an increase in local and state spit tobacco taxes.

OBJECTIVE PT6: Reduce the number of pregnant women who smoke during the last three months of

pregnancy to 25% and number of pregnant women who use spit tobacco to 15% by 2017.

Baseline: 30% smoke, 18% use spit tobacco/Iqmik (PRAMS 2008)

Activity a: Develop and assess the effectiveness of Alaska Native specific tobacco use interventions for women of reproductive age, including pregnant and post partum women.

Activity b: Increase Alaska Native specific tobacco control initiatives and educational resources targeting pregnant and post partum women to assure comprehensive, culturally appropriate media messages reach the intended audience.

OBJECTIVE PT7: Reduce the percentage of Alaska Native youth smokers to 15% by 2017.

Baseline: 20% of Alaska Native youth smoke tobacco (YRBS 2011)

Activity a: Support Alaska Native specific tobacco control media and education initiatives to assure comprehensive, culturally appropriate media messages reach Alaska Native youth.

Activity b: Encourage partners within rural communities ask parents of young children and youth, if they use tobacco or expose family members to second hand smoke and then determine their readiness to quit and advise them accordingly.

Activity c: Partner with non healthcare providers to address tobacco use with parents of young children (Don't start!) at the community level.

OBJECTIVE PT8: Support collaborative advocacy efforts to pass clean indoor air policies and tobacco tax increases at local levels and statewide.

Baseline: No statewide clean indoor air policy exists in 2010

Activity a: Assist with efforts to establish statewide clean indoor air policy through collaboration with Alaska Tobacco Control Alliance (ATCA) and other advocacy partners.

Activity b: Assist with efforts to increase local or statewide tobacco taxes through collaboration with ATCA and other advocacy partners.

Activity c: Encourage the Alaska Federation of Natives to pass a resolution supporting a statewide clean indoor air ordinance.

Nutrition and Obesity

Goals, Objectives & Strategies for Nutrition

GOAL: Alaska Native people will make healthy nutrition choices for cancer prevention.

OBJECTIVE PN1: Increase to 32% the proportion of Alaska Native adults 18 and older who are at their normal weight with a Body Mass Index (BMI) below 25 by 2017.

Baseline: 27.5% (BRFSS 2009)

Activity a: Provide resources for Alaska Native people about the links between diet and cancer, including the importance of maintaining a diet rich in plant-based foods, reducing the consumption of store-bought animal fat and attaining and maintaining healthy body weight.

Activity b: Provide resources for health care providers to increase their capacity to educate Alaska Native people on the importance of maintaining a healthy diet.

Activity c: Provide resources for new mothers on the importance of the early introduction of traditional foods for infants and young children.

Activity d: Revise Traditional Food Guide (published in 2008) to expand distribution to cancer survivors, providers, teachers and general public for use in traditional and non-traditional settings.

Activity e: Study options for potential changes in WIC program to allow traditional foods.

Activity f: Develop booklet for WIC program to introduce traditional foods to children during infancy.

Activity g: Support the inclusion of traditional foods in daily diets of youth in residences and institutions where there is a high percentage of Alaska Native youth.

Activity h: Encourage drinking water for increased hydration and in place of soft drinks and other sugared drinks.

Activity i: As a third component of the traditional Native food guide activities, develop a DVD focusing on elders and youth learning about traditional gathering and food preparation.

OBJECTIVE PN2: Reduce the percentage of Alaska Native students who are overweight or obese to 15% overweight and 10% obese by 2017.

Baseline: 17% overweight, 12% obese (YRBS 2009)

Activity a: Identify barriers to healthy eating in communities. Work with diabetes and other tribal programs to identify ways to overcome barriers.

Activity b: Develop an activity workbook for Alaska Native students aged 8-10 emphasizing the importance of making healthy food choices including traditional foods.

Activity c: Utilize existing adolescent social networking sites to introduce use of traditional foods.

OBJECTIVE PN3: Increase to 18% the proportion of Alaska Native adults 18 and older who eat at least five servings of fruits and vegetables every day by 2017.

Baseline: 15% (BRFSS 2009)

Activity a: Develop educational materials for Alaska Native adults to increase their awareness of the importance of eating five or more servings of fruits and vegetables every day.

Activity b: Introduce material to communities providing information on plate sizes and percentages of vegetables, protein and carbohydrates.

OBJECTIVE PN4: Increase to 18% the proportion of Alaska Native students who eat at least five or more servings of fruits and vegetables every day by 2017.

Baseline: 16% (YRBS 2009)

Activity a: Develop media messages aimed at Alaska Native adolescents to increase their awareness of the importance of eating five or more servings of fruits and vegetables every day.

Activity b: Identify tribal health program partners to collaborate with to deliver effective culturally appropriate services and education.

Activity c: Partner with hospitals in and outside of Alaska to support availability of traditional foods for Alaska Native patients who must remain out of state for care.

Physical Activity

Goal, Objectives & Strategies for Physical Activity

GOAL: Alaska Native people will make healthy physical activity choices for cancer prevention.

OBJECTIVE PP1: Increase to 70% the proportion of Alaska Native adults 18 and older who meet the

2008 Physical Activity Guidelines for Americans by 2017. (www.health.gov/paguidelines/pdf/paguide.pdf)

Baseline: 65% (BRFSS 2009)

Activity a: Increase public awareness of the benefits of physical activity.

Activity b: Encourage communities to provide physical activity opportunities and establish policies that promote physical activity.

Activity c: Develop culturally appropriate media campaign emphasizing unique in-home small space opportunities for brief bursts of activity.

OBJECTIVE PP2: Increase to 37% the proportion of Alaska Native high school youth who were physically active for a total of at least 60 minutes per day for five or more of the past seven days by 2017.

Baseline: 35% (YRBS 2009)

Activity a: Increase the number of schools that provide physical activity opportunities and establish policies that promote physical activity.

Activity b: Encourage safe areas for physical activity including playgrounds, sidewalks, and designated areas for walking, basketball, baseball, and similar activities.

Activity c: Develop campaign to reduce "screen" time and increase physical activity.

Environmental Contaminants

Goal, Objectives & Strategies for Environmental Contaminants

Goal: Reduce the exposure of Alaska Native people to harmful levels of carcinogenic environmental contaminants.

OBJECTIVE PE1: Educate Alaska Native people about ways to reduce harmful exposure to contaminants.

Baseline: Currently there are studies underway within ANTHC on the impact and health effects of climate change and large development projects. The ANTHC publication "Alaska Native Traditional Food Guide" is available statewide.

Activity a: Raise awareness of the benefits and risks associated with traditional diets.

Activity b: Increase awareness about

health risks associated with asbestos and radon exposure.

Activity c: Develop culturally appropriate materials that discuss the possibility of environmental contamination, but highlighting that other changeable risk factors including tobacco and obesity are more harmful to one's health.

Infectious Agents

Goal, Objective & Strategies for Infectious Agents

GOAL: Reduce cancer deaths in Alaska Native people due to infectious agents.

OBJECTIVE PI1: Increase awareness among Alaska Native people of the relationship between certain infectious diseases and cancers.

Baseline: New studies show improvement in areas such as HPV vaccination, *H. pylori* and hepatitis.

Activity a: Promote the use of Human Papillomavirus (HPV) vaccination for cervical cancer prevention through statewide education and outreach campaigns.

Activity b: Monitor emerging science investigating the relationship between infectious agents and cancer.

Chapter 3 SCREENING & EARLY DETECTION

Breast and Cervical Cancer

Goals, Objectives & Activities for Breast and Cervical Cancer Screening

GOAL: Reduce death from breast and cervical cancer.

OBJECTIVE SB1: Increase the percentage of Alaska Native women aged 40 years and older who receive mammograms every two years to 66% and cervical

cancer screenings to 87% by 2017 (Healthy People 2020 targeted a 10% improvement by 2020).

Baseline: 63% of Alaska Native women aged 40 years and older had mammography screening in the previous two years and 83% of Alaska Native women had a cervical cancer screening test done in the previous three years (BRFSS 2008.)

Activity a: Support the development and distribution of health education material for breast and cervical cancer screening.

Activity b: Promote the importance of breast and cervical screening to women through their workplace in businesses with a high proportion of Alaska Native employees.

OBJECTIVE SB2: Maintain collaboration with the Alaska Breast and Cervical Cancer Early Detection Programs through active participation in the Alaska Breast and Cervical Health Partnership through 2017.

Baseline: Collaboration began in 2006.

Activity a: Maintain a Letter of Cooperation with CDC National Breast and Cervical Cancer Early Detection Programs, CDC Colorectal Cancer Screening Programs and CDC funded Alaska Cancer Registry.

Activity b: Jointly produce at least one patient education resource on breast cancer screening education and awareness annually.

Activity c: Collaborate on one continuing education event for breast and cervical cancer providers annually.

Activity d: Contribute biannually to the Breast and Cervical Health Partnership social media sites and encourage women to use them for breast and cervical screening information and education.

OBJECTIVE SB3: Increase opportunities for tribal breast and cervical cancer programs throughout Alaska to share best practices for screening by 2017.

Baseline: No organized opportunity for sharing best practices among breast and cervical screening providers in Alaska exists in 2011.

Activity a: Identify and share practices within NBCCEDP funded programs that can be adapted and used by other breast and cervical screening programs in Alaska.

Activity b: Organize an opportunity for breast and cervical cancer screening programs to network with other breast and cervical programs in Alaska.

Colorectal Cancer

Goals, Objectives & Activities for Colorectal Cancer

GOAL: Reduce the incidence of colorectal cancer.

OBJECTIVE SC1: Increase percentage of Alaska Native people 50 years and older who are screened for colorectal cancer (colonoscopy or flexible sigmoidoscopy) to 80% by 2017 (goal set by the CDC CRC Control Program is 80% by 2014).

Baseline: Colorectal cancer screening rates in Alaska Native people are reported at 50% (BRFSS 2008). More recent GPRA reports indicate colorectal cancer screening rates of 57% (GPRA 2012).

Activity a: Provide colorectal cancer awareness and education events in twenty-five tribal health communities including the seven communities who have hospitals with CRC screening capacity to increase screening among Alaska Native people.

Activity b: Use statewide media to increase awareness about colorectal cancer screening.

Activity c: Promote colorectal cancer screening education for Alaska Native men and women through their workplace in businesses with a high proportion of Alaska Native employees.

Activity d: Assist CDC in SECAP II, a survey of the capacity for CRC screening in Alaska including both tribal and non-tribal facilities and providers.

Objective SC2: Maintain Alaska Colorectal Cancer Partnership in conjunction with State of Alaska CCC Program through 2017.

Baseline: Collaboration began in 2006.

Activity a: Collaborate with CDC sponsored Colorectal Cancer Control Programs in Alaska, including regular monthly meetings. Complete two joint projects each year.

Activity b: Support policy and advocacy efforts of the CRC Partnership to increase insurance coverage for CRC screening among self-insured employers.

Activity c: Contribute quarterly to the CRC Partnership social media pages and encourage people to use the pages to access colorectal cancer education resources.

Prostate Cancer

Goals, Objectives & Activities for Prostate Cancer

GOAL: Increase informed decision making regarding prostate screening among Alaska Native men.

OBJECTIVE SP1: Understand current practices among primary care clinicians in the ATHS with regard to prostate screening and patient care by 2017.

Baseline: Limited information is available about current practices in prostate screening in ATHS in 2010.

Activity a: Survey primary care clinicians in the ATHS to better understand attitudes toward and practices surrounding prostate cancer screening, follow-up and survivor care.

Activity b: Provide primary care providers with the latest information regarding recommendations for prostate screening.

OBJECTIVE SP2: Develop and distribute educational material to Alaska Native men and their health care providers regarding prostate screening recommendations by 2017.

Baseline: Limited prostate screening educational materials specific to Alaska Native men are available in 2010.

Activity a: Develop patient information materials on informed decision making for Alaska Native men.

Activity b: Distribute materials throughout the ATHS

OBJECTIVE SP3: Develop and participate in activities designed to support prostate and testicular cancer survivors by 2017.

Baseline: Few activities centered on prostate and testicular cancer education are available to Alaska Native men.

Activity a: Organize annual Men's Retreats for prostate and testicular cancer survivors emphasizing the importance of continued routine prostate screenings.

Activity b: Support activities of the Alaska Prostate Cancer Coalition.

Activity c: Support the State of Alaska CCC Program in a survey of prostate cancer survivors to better understand the needs of men in Alaska.

Emerging Science

Goals, Objectives & Activities for Emerging Science

GOAL: Investigate the availability and appropriateness of new tests and procedures to prevent, detect, diagnose, and treat cancer survivors and those receiving palliative care and incorporate them in the cancer program.

OBJECTIVE SO1: Educate and promote new cancer screening and early detection tests as recommended by national organizations by 2017.

Baseline: No formal tracking system of new screening tests exists in 2010

Activity a: Assist May Cancer Center in organizing an annual cancer conference at ANMC.

Activity b: Review literature to identify state of the art cancer screening opportunities for Alaska Native people.

Activity c: Monitor outcomes of Alaska Native Epidemiology Center research on fecal immunochemical testing (FIT) and stool DNA testing for Alaska Native people.

Chapter 4 DIAGNOSIS & TREATMENT

Goals, Objectives & Activities for Diagnosis and Treatment

GOAL: To diagnose cancer as early as possible using the least invasive and most comprehensive procedures available. When cancer is diagnosed, treat the patient and family with the most appropriate therapy as close to home as possible.

OBJECTIVE DT1: Support efforts to achieve state of the art diagnostic and treatment services at ANMC and at specialty and field clinics by 2017.

Baseline: Recognized need in to monitor and support new diagnostic and treatment services in 2010.

Activity a: Partner with ANMC Cancer Committee to identify and support cancer diagnostic and treatment services.

Activity b: Support state and national efforts to reduce cancer drug shortages.

Activity c: Develop patient education materials which explain diagnostic and treatment procedures and helps patients understand the process of making a cancer diagnosis and developing a treatment plan.

Activity d: Investigate the use of a standard oncology formulary throughout the ATHS.

OBJECTIVE DT2: Increase the number of ANMC and ATHS oncology nurses certified by the Oncology Nursing Society (ONS) to six by 2017.

Baseline: Four nurses within the ATHS are certified in 2010. Eighty-six nurses have been trained to deliver chemotherapy since 2006 (ANMC Oncology Clinic 2011).

Activity a: Identify and support ANMC oncology nurses interested in becoming ONS certified.

Activity b: Support chemotherapy instruction training and the efforts of nurses in regional facilities to provide chemotherapy.

OBJECTIVE DT3: Coordinate cancer patient navigation services at ANMC, regions and communities to ensure timely and efficient cancer care coordination by 2017.

Baseline: Cancer patient navigation services are limited in the ATHS in 2010. The Oncology Social Worker (new position since 2005) and Oncology Clinic case management staff currently provide this service at ANMC.

Activity a: Identify collaborative and financial means to support establishing a coordinated cancer patient navigation program.

Activity b: Develop patient education materials applicable to diagnosis and treatment.

Activity c: Support the development of paper end-of-treatment summaries for cancer patients with electronic health records system until the EHR component is available at ANMC.

OBJECTIVE DT4: Establish a pain and symptom management program to ensure that cancer patients receive timely and effective pain and symptom therapy regardless of whether they are treated at ANMC, regional hospitals, or

villages by 2017.

Baseline: *There is no comprehensive, integrated cancer pain and symptom program in the ATHS in 2010.*

Activity a: Collaborate with ANMC Pharmacy, palliative care providers, and others to establish a pain and symptom management program including better access to medications throughout the ATHS.

Activity b: Use findings from 2010 patient self-identification of symptoms project to better coordinate with regional and village healthcare providers.

OBJECTIVE DT5: Implement a clinical trials plan at ANMC by 2017.

Baseline: *Clinical trials are not available at ANMC in 2010.*

Activity a: Develop clinical trials communication plan

Activity b: Develop patient and community education materials explaining clinical trials.

Activity c: Develop and support policy changes necessary to offer clinical trials.

Chapter 5 **SURVIVORSHIP**

Goal, Objectives & Activities for Survivorship

GOAL: Alaska Native cancer patients and their families will have access to programs and services that address their physical, mental, spiritual and practical needs to improve the length and quality of life.

Objective SS1: Develop a comprehensive Survivorship Plan for the ATHS to guide the development of new programs and services for cancer survivors. The plan will support cancer survivors and address their physical, mental, spiritual, and practical concerns by 2017.

Baseline: *There is no Survivorship Plan for Alaska Native cancer survivors in 2010.*

Activity a: Perform a needs assessment of Alaska Native cancer survivors.

Activity b: Identify gaps in existing cancer survivorship programs within the ATHS and prioritize needed resources and programs.

Activity c: Determine provider knowledge regarding survivor issues.

Activity d: Complete a comprehensive five year Survivorship Plan for ATHS.

Activity e: Support the development of two resources identified in the Survivorship Plan.

Activity f: Develop a resource plan to anticipate funding needed to support survivorship efforts in the future.

OBJECTIVE SS2: Enhance clinical care management and follow-up care for patients diagnosed with cancer to minimize recurrences, detect secondary cancers early, and ensure maximum years of quality of life by 2017.

Baseline: *A comprehensive program for providing follow-up care to patients at the end of cancer treatment does not exist within the ATHS in 2010.*

Activity a: Complete a paper end of cancer treatment summary for each cancer patient and incorporate it into ATHS electronic medical record systems.

Activity b: Develop a tracking system to identify survivors and standardize recommended early detection and screening recommendations.

Activity c: Increase educational opportunities for providers on new clinical practices addressing survivorship issues.

OBJECTIVE SS3: Encourage and support the delivery of established survivorship programs by regional tribal health organizations by 2017.

Baseline: *ANTHC has established survivorship programs that can now be adopted by regional tribal health organizations.*

Activity a: Support at least two Men's Retreats for Cancer Survivors organized in regions.

Activity b: Support at least two Camp Coho events.

Activity c: Encourage and support the development of community based support groups working with patients and families of survivors to provide assistance to cancer patients returning home after cancer treatment.

Activity d: Support training for six individuals willing to facilitate regional cancer support groups.

Activity e: Review and revise Traditional Food Guide for Cancer Survivors published in 2008.

Activity f: Coordinate with the ANTHC Behavioral Health Aide (BHA) Program to include training for Aides on the emotional and psychological needs of cancer survivors.

Chapter 6 **PALLIATIVE CARE**

Goals, Objectives & Activities for Palliative Care

GOAL: Provide active total care of the body, mind and spirit of a patient and family and to help the patient achieve the best quality of life possible as close to home as possible.

OBJECTIVE PC1: Develop and implement a Palliative Care Program at ANMC for appropriate outpatient clinics and inpatients by 2017.

Baseline: *A palliative care program does not exist at ANMC.*

Activity a: Identify needed resources and secure support for palliative care consultant team

Activity b: Develop policies and procedures manual for integration of Palliative Care Program into ANMC quality of care and other essential programs.

Activity c: Design regional and community program access guidelines.

Activity d: Conduct an International Telehealth Palliative Care Symposium annually or as funding is available.

Objective PC2: Establish remote Palliative Care Consultation Program component by 2017

Baseline: *A remote Palliative Care Consultation Program does not exist in 2011.*

Activity a: Identify resources needed to support the following and implement as feasible:

- Registered nurse to return with patient to home community after discharge from ANMC for initial patient/family teaching and home setting evaluation.
- With recommendations from regional and community healthcare providers, determine the type and level of palliative care consultation support needed to support patients and providers in the regional hospital setting and home communities.
- Utilize ANTHC Telehealth program to coordinate consultations with providers, patients, families and communities at regional hospitals, CHAP clinics and patient homes to optimize patient/family quality of life, reduction of signs and symptoms and reduced travel.

Activity b: Establish ATHS-wide palliative care formulary.

OBJECTIVE PC3: Determine need for and feasibility of establishing hospice programs by 2017

Baseline: There are no volunteer or Medicare-certified hospices for remote communities in Alaska in 2011.

Activity a: Monitor third party reimbursement and policy changes for palliative/hospice care.

Activity b: Educate legislators, healthcare providers and communities about the need to support community-based palliative care/hospice programs.

Chapter 7 SURVEILLANCE & RESEARCH

Goal, Objective & Strategies for Surveillance and Research

GOAL: Utilize complete, accurate, and timely data on cancer in Alaska Native people to provide the basis for cancer programs and services.

OBJECTIVE SR1: Support the gathering and maintenance of data systems to understand the cancer related needs of Alaska Native people through 2017

Baseline: The Alaska Native Tumor Registry provides data for use in cancer research and program planning and implementation in 2011.

Activity a: Support the efforts of the Alaska Native Tumor Registry to continue to gather and report cancer data on

Alaska Native people.

Activity b: Develop and implement communications plan to inform and educate Alaska Native people and providers of the importance of clinical trials.

Activity c: Support the development of cancer clinical trials at ANMC and ANTHC.

Activity d: Maintain ongoing review of research outcomes to improve cancer prevention and care.

Objective SR2: Promote an understanding of cancer data among Alaska Native people.

Baseline: The Cancer Program has limited methods of explaining cancer data that also engages community in behaviors and activities that influence that data.

Activity a: Support efforts in health literacy and understanding of cancer data.

Activity b: Develop a booklet that includes examples of cancer data and suggests ways that an individual, family or community can influence the data.



Photo by George Nickerson

APPENDIX 2

The Alaska Native Tribal Health Consortium, the Alaska Tribal Health System, and the History of Cancer Planning in Alaska/Evaluation of Cancer Plan

The Alaska Native Tribal Health Consortium

Since 1970, a statewide system of regional and local tribal health providers has been in existence to provide health care to Alaska Native people. This unique system provides access to a comprehensive, integrated, and tribally owned and controlled health care delivery system.

For more than 30 years, the Alaska Native Health Board (ANHB) served as a statewide organization for the purpose of “promoting the spiritual, physical, mental, social and cultural well-being and pride of Alaska Native People.” Primarily an advocacy organization for Alaska Native people, the ANHB Board of Directors represented the tribes and tribal organizations that carried out health programs throughout Alaska. Through ANHB, tribes and tribal organizations coordinated activities to develop common objectives and undertake statewide projects.

In 1994, several tribal health organizations joined together to form a compact that provided the opportunity for direct government-to-government negotiations between compact signers and representatives of the federal government through the Indian Health Service (IHS). Tribes and tribal organizations began to manage and operate hospitals and clinics. It allowed them to make faster and more efficient decisions that better addressed the health care needs and concerns among Alaska Native people. Over the past ten years, more tribes and tribal organizations joined the Compact.

In 1997, after years of inter-tribal discussion and negotiation with the IHS, the Alaska Native Tribal Health Consortium (ANTHC) was formed to promote the American Indian/Alaska Native vision of “self-governance and self-determination”. ANTHC is a statewide 501(c) 3 non-profit health services organization owned by the Alaska Native people. A 15-member Alaska Native Board of Directors representing 229 tribes and 39 tribal health organizations across Alaska governs ANTHC. The Consortium entered into a self-governance agreement (the Alaska Tribal Health Compact) with the IHS for management of all statewide health services formerly provided by that agency for Alaska Native people. ANTHC is the largest tribal self-governance entity in the United States. Unlike most boards of a corporation of this size, the board

is made up of Alaska Native consumers--comprised of fishermen, housewives, former village-based health workers, community activists, and others appointed by their tribes to represent them. It exists to “provide the highest quality health services for all Alaska Native people.”

The ANTHC vision is for “Alaska Native people to be the healthiest people in the world”. Along with that vision is the goal to have Alaska Native people trained to provide all levels of Alaska Native healthcare. Until there are enough American Indian/Alaska Natives trained as healthcare providers and administrative staff, non-Native people are hired to provide those services. Oversight continues to be provided by the ANTHC Board of Directors. The Board approves plans, programs, services and budgets.

The Alaska Tribal Health System

The Alaska Tribal Health System (ATHS) is a large network of village-based clinics, sub-regional clinics, regional hospitals, and a large tertiary care facility (Alaska Native Medical Center or ANMC). ANMC, a 150-bed hospital, is Indian Country’s largest and most sophisticated medical center and is jointly managed by ANTHC and the Southcentral Foundation. The ATHS is complex in that it includes cradle-to-grave comprehensive care for eligible beneficiaries at multiple facilities of varied capacity, spread across the state.

The ATHS is organized around five levels of care:

- ◆ **Village-based services** are provided by Community Health Aide/Practitioners working in village clinics (180 sites in rural Alaska, majority without road access) and other health care workers such as behavioral and dental aides.
- ◆ **Sub-regional services** are provided by mid-level practitioners serving several village
- ◆ **Regional services** are provided at six regional primary care hospitals in Barrow, Nome, Kotzebue, Bethel, Dillingham and Sitka. Many other healthcare services are provided by the tribal organizations in these areas and governed by their own board of directors.
- ◆ **Statewide tertiary and specialty services** are provided at the Alaska Native Medical Center (located in Anchorage). ANMC multi-specialty outpatient clinics record more than 287,000 visits, perform over 10,000

surgical procedures, and admit over 8,000 patients each year. ANMC has also earned the distinction of being certified as the only Level II Trauma Center hospital in Alaska, placing it as the highest quality emergency treatment provider in the state.

- ◆ **Contact health services** include coverage for private sector referrals beyond the direct care system.

As the major providers of healthcare within the ATHS, ANTHC and ANMC, incorporate organizational behaviors, practices, attitudes, and policies that are respectful and responsive to cultural diversity in the broader definition that includes socioeconomic status, age, religion, sexual orientation, gender, physical and mental capacity and other differences.

Cancer Program planning and implementation

In 1990, the State of Alaska Division of Public Health was awarded a "Data-Based Intervention Research Cooperative Agreement" by the National Cancer Institute to conduct a cancer control project using state cancer data to plan and undertake prevention and control activities. The project focused on tobacco-related, breast, and cervical cancers as they offered significant opportunities for prevention and early detection.

In 1994, the first State of Alaska Cancer Control Plan was written by the Alaska Division of Public Health, Section of Epidemiology and funded by the Division of Cancer Prevention and Control, National Cancer Institute. While these efforts were comprehensive and written to include Alaska Native people, the Alaska Tribal Health System has unique challenges and systems of care which were difficult to address in a statewide plan.

Although overall cancer mortality rates in the United States declined through the 1990s, Alaska Native cancer rates increased. From 1994 to 1998 the Alaska Native age-adjusted average annual mortality rate was thirty percent higher than that of U.S. Whites. Alaska Native people were forty percent more likely to die of lung cancer than U.S. Whites and demonstrated elevated mortality rates for several other smoking-related cancers as well. Also, Alaska Native people are at excess risk for nearly all cancers of the digestive system. Research in the area concluded that the burden of cancer on the Alaska Native healthcare system will continue to increase as the population ages and that intensified efforts to modify behavioral risk factors were needed.

These findings, coupled with the knowledge of the unique cultural differences and geographic barriers faced by many Alaska Native people, prompted ANTHC to apply to the

Centers for Disease Control and Prevention (CDC) for assistance in writing a comprehensive cancer plan for Alaska Native people. In 2004, ANTHC received the grant and began a comprehensive planning process which resulted in this first Alaska Tribal Health System Comprehensive Cancer Plan, 2005-2010. The State of Alaska also received a grant to update their 1994 cancer plan. Alaska Native people are the largest minority in Alaska and the ATHS is often the only provider of healthcare in Alaska's remote communities. The ATHS is uniquely positioned to address many issues across the spectrum of cancer planning since it provides healthcare across a large and mostly road less state using innovative approaches refined and tested over many years.

The ATHS Comprehensive Cancer plan, the first of its kind, addresses all aspects of cancer including prevention, screening and early detection, diagnosis, treatment, survivorship and palliative care. Over 130 healthcare providers, tribal health board members, cancer survivors, tribal representatives and others worked hard as part of eight work groups to develop the cancer plan. Many others offered expertise in specific areas. After spending three years of planning, in July 2006 ANTHC received an Implementation Grant from CDC to work on the goals, objectives, and strategies prioritized in this plan. The plan will also be a valuable tool for all Alaska healthcare organizations as they seek to address and provide "the highest quality of health care" for the people throughout the state.

Evaluation

The purpose of developing and implementing a comprehensive cancer plan is ultimately to reduce cancer incidence, morbidity, and mortality and to improve quality of life. To determine whether the purpose is being achieved, the plan will be evaluated.

ANTHC has contracted with a nationally recognized consultant with expertise in cancer programs to provide program evaluation for the Cancer Plan. The evaluation will focus on processes, impacts (short-term results), and outcomes. The process evaluation will gather specific information such as the number of people and organizations who receive a copy of the cancer plan. The impact evaluation focuses on the short-term results of the program and whether the priorities and strategies are being addressed. The outcome evaluation will measure the impact and success of plan objectives. Where possible, measurable objectives have been identified and included in the plan. Baseline data will be used to measure progress and determine the effectiveness of plan strategies.

APPENDIX 3

2010 ATHS Cancer Survey Results Summary

The Alaska Native Tribal Health Consortium Cancer Program conducted a survey across the Alaska Tribal Health System (ATHS) in November 2010. The purpose of the survey was to gather opinions as to how well cancer planning efforts were implemented from 2006-2010. Survey results were used to update the Comprehensive Cancer Plan, 2011-2017.

The electronic survey was distributed across ATHS to tribal leaders, physicians, midlevel practitioners, nurses, community health aide/ practitioners, health educators, administrators, social workers, patient navigators, and other health professionals. A total of 227 people participated in the survey. Participants responded to ten questions regarding tribal health system cancer program activities in the past five years.

Participants also provided comments on two questions:

Do you think cancer is more or less difficult to discuss than five years ago?

"Having cancer has lost some of its 'stigma', people understand now that it is more of a chronic disease since there are so many treatment options available. People are living longer and are able to have their symptoms managed so that they can continue to enjoy their time with their families."

"Everyone now knows someone who has or has had cancer. I believe the awareness and education about cancer is more present in our communities."

"There is more information (brochures, videos, PSA's) out there about the various types of cancer and I think that people are more aware."

"I always find it hard to talk about cancer although I am better equipped to talk about it and can discuss cancer with patients and families when I need to."

"We still find many myths about cancer in our communities."

What could the Alaska Native Tribal Health Consortium do to better address cancer in your community?

"We need more outreach to the communities and more awareness to educate communities on prevention."

"Better access to cancer screening and more support programs for families with information available on services available."

"Continue to fund cancer prevention and screening programs as aggressively as possible."

"We need palliative care and hospice services."

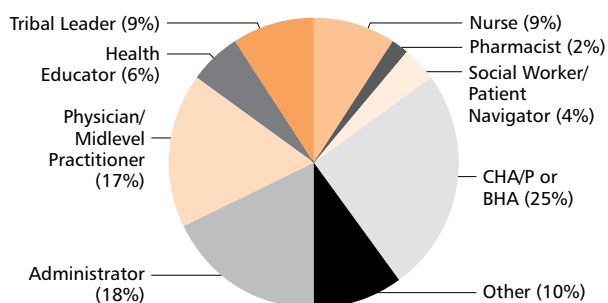
"Focus on families that have a history of cancer."

Survey Participants

227 people participated in the survey. Only 208 provided discipline information. Participants could choose multiple disciplines, therefore there were 240 responses.

Who participated in the Cancer Planning Survey

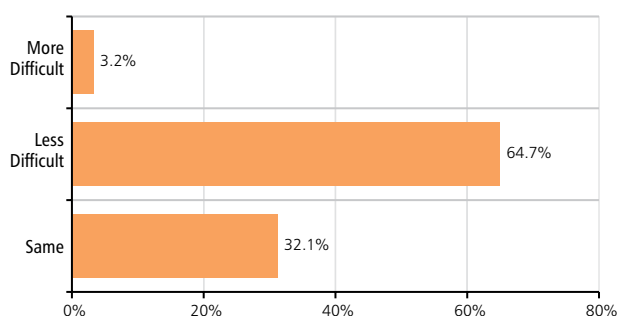
N=208



Talking About Cancer

Survey respondents were asked if they believe cancer was more difficult, less difficult or the same to talk about as five years ago. 64.7% of healthcare providers and tribal health stakeholders reported that cancer was less difficult to talk about than five years ago. The response rate did not significantly change by profession.

Do you believe that cancer is more or less difficult to talk about than it was five years ago? N=216

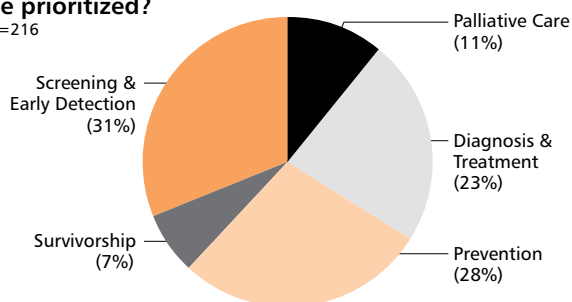


Prioritizing cancer components

When asked to prioritize cancer control program efforts respondents ranked cancer control areas from one to five, with one being the most important and five being the least. Each choice could only be ranked once. Of the 216 people who responded to this question, screening/early detection and prevention program ranked as the most important.

How should 2011-2015 ATHS Cancer Programs be prioritized?

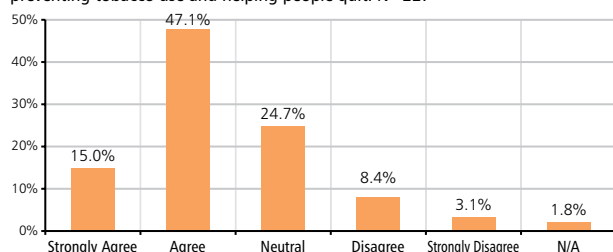
N=216



Participants were asked five questions regarding cancer control programs. Each question related to one of the five major areas of cancer control. Results are as follows:

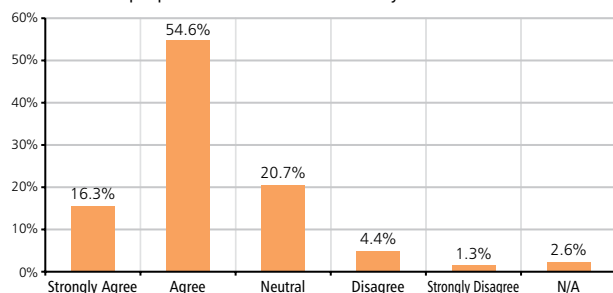
Prevention/ Tobacco Control Efforts

In the past five years, the Alaska Tribal Health System has gotten better at preventing tobacco use and helping people quit. N=227



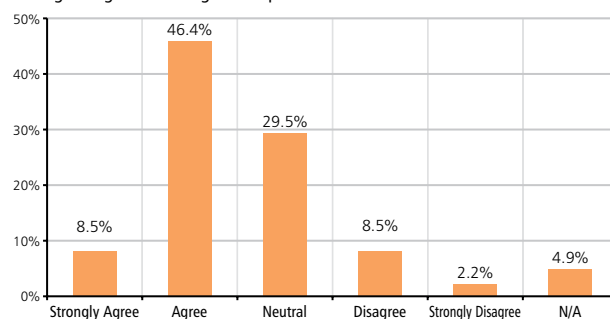
Cancer Screening and Early Detection

In the past five years, I have seen an increase in cancer screening and early detection programs (mammograms, pap smears, PSA, testing, colonoscopy) available to the people in the Alaska Tribal Health System. N=227



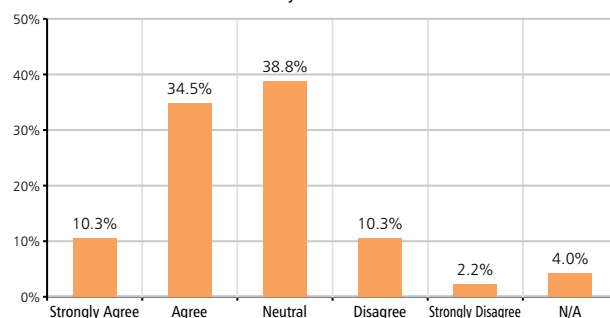
Treatment of Cancer Patients

In the past five years, the Alaska Tribal Health System has been doing a better job at diagnosing and treating cancer patients. N=224



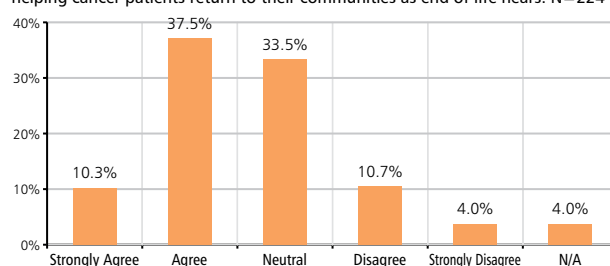
Cancer Survivorship

In the past five years, I have seen an increase in programs and services for cancer survivors in the Alaska Tribal Health System. N=224



Palliative Care

In the past five years, the Alaska Tribal Health System has gotten better at helping cancer patients return to their communities as end of life nears. N=224



Conclusion

The ATHS Cancer Program Survey received a high response rate from ATHS health professionals and tribal leadership. CHA/PS was the largest group of respondents by discipline with 60 participating in the survey.

Participants of the survey reported that they believe that cancer is less difficult to talk about than five years ago. Only 3.3% felt cancer was more difficult to discuss. While many feel cancer is still a little difficult to discuss, Alaska Native educational materials and other health messages better explain cancer and assist with provider to patient discussions. New cancer drugs and treatments help patients live longer, healthier lives after a cancer diagnosis.

More than half of respondents reported an increase in prevention programs, cancer screening/early detection programs and diagnosis/treatment services throughout the ATHS. Fewer

respondents believed services for cancer survivors and palliative care had increased. Less than 20% reported fewer services available. When participants prioritized cancer program components, Survivorship and Palliative care services were ranked lower than Prevention, Screening and Early Detection programs.

Recommendations for future cancer program planning goals:

- Prioritize prevention – especially tobacco control efforts
- Prioritize screening and early detection programs
- Increase availability and awareness of survivorship and palliative care programs
- Distribute survey in 2014 to the same participant list to compare results from 2010 survey



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